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**THE PROCESS OF PSYCHOLOGICAL ADJUSTMENT  
TO MULTIPLE SCLEROSIS:**

**Comparing the Roles of Appraisals, Acceptance, and  
Cognitive Fusion.**

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# Abstract

## Background:

Research in psychological adjustment to multiple sclerosis (MS) suggests that the way individuals appraise their condition can have an impact upon their psychological well-being and adjustment to their condition. Such research has influenced the development of Cognitive Behavioural Therapy (CBT) interventions in this population. In recent years, Acceptance and Commitment Therapy (ACT) has gathered increasing interest in relation to chronic health conditions. ACT does not target the *content* of thought, but rather focuses on the *contexts* in which thought occurs (i.e. how individuals relate to their experiences).

## Aim and Primary Hypothesis:

A cross sectional design was used to compare the extent to which cognitive appraisals and ACT constructs ('acceptance' and 'cognitive fusion'), mediate the relationship between physical symptoms of MS and psychological adjustment outcomes. It was hypothesised that in comparison to cognitive appraisals, ACT constructs would serve as stronger mediators of the relationship between physical symptoms of MS and outcome measures. This study also piloted a newly adapted measure of MS related acceptance, the Multiple Sclerosis Acceptance Questionnaire (MSAQ).

## Method and Results:

Participants ( $N = 133$ ) completed self-report measures of: MS symptom severity, various cognitive constructs (cognitive appraisals and ACT constructs), symptoms of psychological distress, and satisfaction with life. Multiple mediation analysis was then used to compare competing mediational hypotheses. In comparison to all measures of cognitive appraisals, the ACT constructs tended to be stronger mediators of the relationship between symptoms and outcome measures (both psychological distress, and satisfaction with life). There was also some evidence for appraisals of

personal control mediating the relationship between symptoms of MS and psychological distress.

**Conclusions:**

This research suggests that ACT constructs may be relevant to the process of psychological adjustment to MS, and that ACT based interventions may be worthy of investigation in this population. The newly adapted MSAQ also shows preliminary promise as a measure of MS related acceptance.

# 1 Introduction

## 1.1 Overview of current research

Multiple sclerosis (MS) is the most common neurological disease among younger adults. There is currently no cure. The disease typically causes progressive physical, and often cognitive, disability which can have a deleterious impact on individuals' quality of life (QoL) and psychological well being.

Research in psychological adjustment to chronic health conditions, such as MS (e.g. Dennison *et al.*, 2009), has shown that the beliefs that individuals form in relation to their health condition, the way they appraise their difficulties, and the coping strategies they employ, can have an impact on their psychological well-being and adjustment to their condition. In line with such underlying theory, psychological interventions based on cognitive behavioural therapy (CBT) are increasingly being developed to target some of the typical problems associated with MS, including depression and fatigue (Dennison *et al.*, 2010). Such interventions are particularly relevant given evidence that poor emotional well-being may be associated with neurological progression of the disease, as psychological states can impact on immune functioning (Kern & Ziemssen, 2008).

In relatively recent years, Acceptance and Commitment Therapy (ACT; Hayes *et al.*, 1999) and other 'third wave' or 'contextual' psychological therapies have gathered increasing interest. Put simply, ACT does not target the *content* of thought as more traditional CBT does, but rather focuses on the *contexts* in which they occur (i.e. how individuals relate to their experiences). ACT has a growing evidence base in terms of its efficacy in improving psychological outcomes and treatment adherence among various chronic health conditions (Hayes *et al.*, 2006; Ost, 2008; Powers *et al.*, 2009; Ruiz, 2010). Despite difference at the level of theoretical underpinning and

technique, ACT appears to show preliminary promise as an effective alternate treatment to traditional CBT for various problems.

The current research employed a cross sectional design to investigate the possible relevance of ACT processes in a MS population. By having participants complete self-report measures of: MS symptom severity, various cognitive constructs (cognitive appraisals, and the ACT constructs of ‘acceptance’ and ‘cognitive fusion’), symptoms of psychological distress, and subjective well-being, it was possible to carry out multiple mediation analysis (Preacher & Hayes, 2008) to explore the extent to which different cognitive constructs mediated the relationship between symptoms of MS and psychological outcome measures. It was hypothesised that ACT constructs would be stronger mediators of the relationship between symptoms of MS and outcome measures, in comparison to cognitive appraisals.

## **1.2 Multiple Sclerosis**

### **1.2.1 Defining Multiple Sclerosis (MS)**

MS is the most common neurological disorder among younger adults, affecting approximately 85,000 individuals in the United Kingdom (Graham, 2002; as cited in Thomas *et al.*, 2009). MS is a progressive and disabling disease, with typical onset occurring between the ages of 20-40, affecting women and men in a ratio of 3:2. The aetiology of the disease is relatively poorly understood, but the current opinion ‘is that it is an autoimmune disorder affecting genetically susceptible individuals’, with the disease process involving ‘inflammation and demyelination of the central nervous system’ (Thomas *et al.*, 2009, p.2).

Three basic types of MS can be distinguished (Thomas *et al.*, 2009):

- 1) Relapse-remitting: characterised by stable phases alternating with relapses (when symptoms worsen or return). The duration of periods of remission and relapse are hugely variable.
- 2) Secondary progressive: following an initial stage of relapse-remitting course, a more progressive phase begins characterised by a steady worsening of the condition.
- 3) Primary progressive: the disease is steadily worsening from the first onset of symptoms.

While some improvement in symptoms can be gained from disease-modifying medication during relapses in the disease (Goodin, 2008), there is no known cure.

### **1.2.2 Symptoms and impacts of the disease**

Thomas *et al.* (2009) summarise the symptoms of MS as including loss in function of: the limbs, balance, bladder or bowel control, and eyesight due to optic neuritis. Other typical symptoms include sexual dysfunction, fatigue, pain, cognitive dysfunction (including processes of concentration, memory, reasoning and judgement), and mood disorders (Mohr & Cox, 2001).

The increasing disability associated with MS has associated ‘psychosocial consequences, including disruptions to life goals, employment, income, relationships, leisure activities, and daily living activities’ (Dennison *et al.*, 2009, p.142). MS can impact significantly upon individuals’ sense of self, and symptoms of anxiety and depression are highly prevalent. Among people with multiple sclerosis (PwMS), depression has a lifetime prevalence of approximately 50 per cent (Sa, 2007), while approximately 35 per cent is reported for anxiety disorders (Korostil & Feinstein, 2007).

Thomas *et al.* (2009) suggest there may be multiple aetiologies for depression in MS. While depression may be a psychological reaction to the disease in some instances, it

may also result from immune dysregulation and brain lesions (Fassbender *et al.*, 1998). Mohr (2002) has suggested that stress may be associated with the development of new brain lesions in MS, and that autoimmune activity may be increased by depression (Mohr, Goodkin *et al.*, 2001).

### **1.2.3 Typical Psychological Interventions in MS**

Given the high prevalence of mood disorders among PwMS, and the negative impact that they can have on QoL and disease activity, there is a need for effective psychological interventions for individuals with MS. Reviews of psychological interventions in MS (Malcomson *et al.*, 2007; Thomas *et al.*, 2009), however, noted that the evidence base is limited.

A series of studies by Mohr and colleagues (Mohr, Boudewyn *et al.*, 2001; Mohr *et al.*, 2005; Mohr *et al.*, 2000) has investigated the efficacy of CBT interventions for depression in MS. Their intervention has included typical CBT techniques such as behavioural activation and cognitive restructuring, along with additional focus on problems such as pain, fatigue and relationship difficulties commonly experienced by PwMS. Dennison and Moss-Morris (2010) observed that while each study had limitations, such as low sample sizes and high attrition rates, CBT has proved an effective intervention for reducing depression in comparison to treatment as usual (TAU) (Mohr *et al.*, 2000), the anti-depressant Sertraline, supportive/expressive group psychotherapy (Mohr, Boudewyn *et al.*, 2001), and individual supportive/expressive psychotherapy (Mohr *et al.*, 2005).

A study by Van Kessel and colleagues (Van Kessel *et al.*, 2008) found CBT to be highly effective in treating MS related fatigue. Outcomes in the CBT group were significantly superior to the comparison group who received relaxation training alone. Post therapy, effect sizes in the CBT group were large (Hedges  $g = 3.03$ ), with participants even showing lower levels of fatigue than healthy controls.

Mohr and colleagues (in preparation; as cited in Dennison & Moss-Morris, 2010) are currently conducting a trial investigating the efficacy of a CBT based stress management program developed specifically for PwMS. The study will conduct brain scans at two-month intervals during treatment to ascertain whether their intervention slows neurological progression of the disease compared to a TAU control group.

The review of psychological interventions in people with MS carried out by Malcomson *et al.* (2007) concluded that there was some evidence for ‘the value of education/information, goal-setting, homework assignments, exercise, discussion forums, and multidisciplinary team support’ (p.1-2). Due to the selection criteria for studies, their conclusions were based only on 3 studies. They excluded all others due to weaknesses in study design, and incomplete reporting of methodological details. The Cochrane review conducted by Thomas *et al.* (2009) included 16 Randomised Controlled Trials (RCTs), and concluded that psychological interventions have potential to be helpful for individuals with MS in many ways. They cautiously suggested that CBT can help individuals cope with, and adjust to, MS and help if they become depressed.

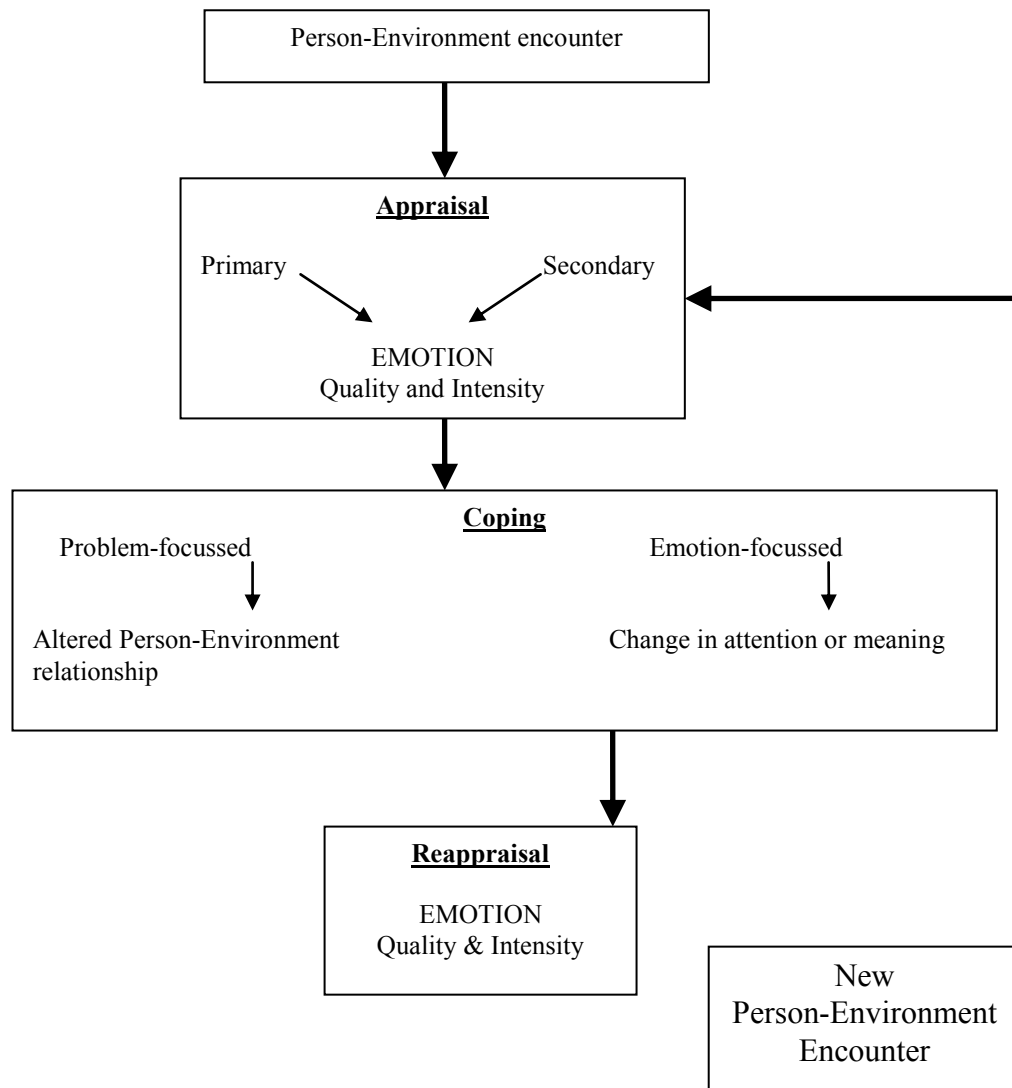
### **1.3 Psychological adjustment to chronic health conditions**

While numerous models have been developed to explain the process of psychological adjustment to chronic health conditions, the following discussion will focus on just two such models: the Stress and Coping Model (SCM) developed by Lazarus and Folkman (1984), and the model of self-regulation, often referred to as the ‘Common Sense Model’ (CSM), developed by Leventhal *et al.* (1984). The focus on these models is due to the dominant influence they have had in this field, along with their high theoretical relevance to the current research.



### **1.3.1 The Stress and Coping Model (SCM)**

Lazarus and Folkman's (1984) SCM is a generic model of stress and coping, which is applicable to a range of stressful contexts, though it has been widely applied to the understanding of adjustment to chronic health conditions. This model posits that adjustment to chronic health conditions is influenced by: firstly, individuals' appraisals of stressors, and secondly, the coping strategies they employed in response to these stressors (Dennison *et al.*, 2009). In the SCM, appraisal and coping are conceptualised as mediators of emotional response. The SCM is represented diagrammatically in Figure 1, below.



**Figure 1 : The Stress and Coping Model**  
(reproduced from Folkman & Lazarus, 1988).

### **1.3.1.1 Appraisals**

Lazarus and Folkman define cognitive appraisal as a process of categorising an encounter (between a person and a given environment) with respect to its significance for well being. They differentiate between primary and secondary appraisals.

Primary appraisals are evaluations of an event's personal significance, thus an event may be classified as 'irrelevant', 'benign-positive', or 'stressful'. The Secondary appraisal involves the evaluation of what an individual believes they can do to cope with a given stressor, and thus guides the use of coping strategies.

Lazarus and Folkman suggest that primary and secondary appraisals interact together in shaping the degree of stress, and the strength and quality of the resultant emotional reaction. For example, if a stressor is appraised as highly threatening, and the individual believes they are powerless and helpless to deal with it, this will result in a high degree of stress.

#### **1.3.1.2      *Coping***

The aforementioned appraisal process, and its attendant emotions, in turn influences the coping strategies an individual may employ. Lazarus and Folkman conceptualise coping as the ongoing cognitive and behavioural processes employed by an individual to manage the internal and external demands placed on them. They differentiate between 'problem focussed' and 'emotion focussed' coping. Problem focussed coping involves acting in the external environment to change the person-environment relations (e.g. learning new skills, or finding alternate means of gaining gratification), often altering the source of stress, while emotion focussed coping involves the regulation of internal states, so includes strategies such as avoidance, minimisation, distancing, selective attention, positive comparisons, and interpreting positive value from primarily negative events (Lazarus & Folkman, 1984).

#### **1.3.1.3      *Reappraisal***

Lazarus and Folkman emphasise that the reappraisal does not differ qualitatively from the initial appraisal, but simply occurs later in the process, and refers to an appraisal based on new information in the environment, including an evaluation of

the individual's coping efforts. Reappraisal can in turn lead to a change in emotion quality and intensity.

#### **1.3.1.4      *Evidence for the relevance of appraisal and stress perception to adjustment to Multiple Sclerosis.***

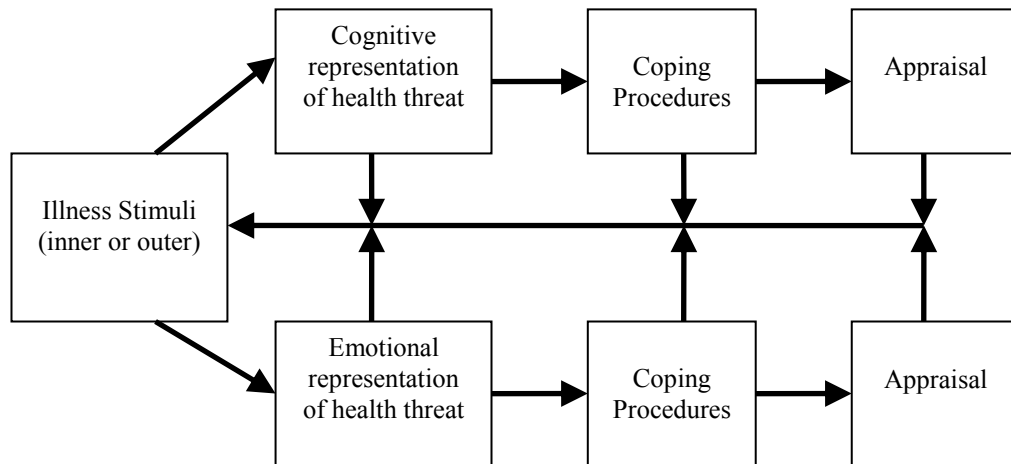
A small number of studies have sought to investigate the link between appraisals of MS related stressors and subsequent adjustment (Dennison *et al.*, 2009). Adjustment has been found to be related to type of appraisal after severity of MS symptoms has been taken into account (Pakenham, 1999; Pakenham *et al.*, 1997; Wineman *et al.*, 1994), with 'threat' appraisals appearing to be the most significantly associated with poor adjustment. Wineman *et al.* (1994) found appraisals to account for 29 per cent of the variance in emotional well-being, while Pakenham and colleagues found appraisals to account for between 6-14 per cent of variance in measures of psychosocial adjustment (Pakenham, 1999; Pakenham *et al.*, 1997).

A recent study conducted by Dennison *et al.* (2009) reviewed eleven studies which investigated the associations between the subjectively experienced degree of stress experienced by PwMS, and adjustment. Across the studies they found an association between perceived stress and adjustment outcomes including depression, anxiety disorders, psychopathology, satisfaction with life, quality of life, and social adjustment.

#### **1.3.2    The Common Sense Model (CSM) of Illness Representations**

While the SCM is a generic model of emotional regulation, the CSM (Leventhal *et al.*, 1984) is concerned specifically with how individuals cope with illness and health threats. According to the CSM, the cognitive representations individuals form in relation to their illness influence their coping strategies and emotional responses. Thus, illness representations are conceptualised as having an influence on adherence to medical treatment and outcome.

The CSM is a “parallel” processing model, in that individuals form both cognitive and emotional representations of their illness (Hagger & Orbell, 2003), as shown in Figure 2 below.



**Figure 2: The Common Sense Model of Illness Representations**

(reproduced from Leventhal *et al.*, 1992)

On the basis of ‘Illness stimuli’, which may include lay information about the disease, information given by external sources, as well as somatic and symptomatic information, individuals form cognitive and emotional representations of their health threat. The individual will then select and implement coping strategies directed towards the management of these cognitive and emotional representations. The CSM postulates that on the basis of illness representations, the coping procedures employed will aim to reduce the symptoms experienced and the level of perceived threat (the cognitive representation), while also reducing the emotional distress associated with the given health condition (the emotional representation). Thus, the procedures employed are tailored to the illness representations. Leventhal *et al.* (1992) give the example of how coping with a minor infection (involving representations of an exogenous cause, short timeline, and low perceived threat) may suggest coping procedures such as taking antibiotics to combat the infection,

drinking fluids to flush out the system, and resting to restore energy levels. Alternatively, a more serious condition such as colon cancer (potentially involving representations of internal cause, longer timeline, and high perceived threat) may necessitate different coping procedures, such as eating a high fibre diet over a long period to clear the intestine of toxins, attempts at positive thinking to boost the immune system, specialist medical help, and seeking social contact in order to express emotions and receive support. It is important to note that, according to the CSM, coping strategies employed are likely to be perceived as correct and necessary by the individual in relation to their illness representations, even if they are considered unlikely to impact upon control of the health condition from an objective standpoint.

The actual behaviours which can constitute ‘coping’ are highly varied. Hagger and Orbell (2003) conducted a meta-analysis of the studies investigating the CSM across different conditions. Their content analysis of coping procedures (captured by different self-report measures across studies) resulted in categorisation under the following general headings: avoidance/denial, cognitive reappraisal, expressing emotion, problem focussed coping (i.e. taking observable behavioural steps to confront and solve problems, both in general and in relation to health threats), and seeking social support. Hagger and Orbell (2003) concluded from their meta-analysis of 45 empirical studies that illness representations and coping strategies do tend to correlate in theoretically predictable ways.

Coping strategies are, in turn, appraised for their effectiveness in dealing with the cognitive and emotional representation of the health threat. As Figure 2 illustrates, the CSM is highly dynamic. The different stages of the CSM do not affect each other uni-directionally or sequentially; it is a more fluid system. The coping strategies employed, and their effectiveness, impact upon illness representations and coping strategies subsequently employed (Leventhal *et al.*, 1984; Leventhal, *et al.* 1992) in a cyclical manner. Illness episodes typically change over time. Somatic sensations of illness fluctuate, and new information about the illness can become available from friends, media, medical professionals, and from the success or failure of coping

strategies. For example, a client suffering from chronic obstructive pulmonary disease (COPD) could be advised that some of their symptoms (e.g. light headedness, shaky legs, and uncomfortable feelings in chest) could be attributable to anxiety in some instances. If the individual entertained this as a possibility and incorporated this information into an illness representation, this could influence coping strategies employed (e.g. reappraisal of symptoms, use of relaxation techniques). If these coping strategies were appraised as successful, and coherent with the new illness representation, this would likely reduce the somatic symptoms of anxiety since they would no longer be perceived as threatening and attributable to COPD, providing further feedback for the modification of illness representations and choice of future coping strategies.

Research across a number of different illness conditions (Hagger & Orbell, 2003) has supported a structure of illness representations consisting of five cognitive dimensions: (1) *identity* – the label of the disease, and the individual's understanding of symptoms; (2) *timeline* – acute, cyclic, or chronic; (3) *consequences* – physical, social, economic, emotional etc.; (4) *causes* – beliefs about the cause of disease (e.g. injury, infection, genetic weakness); (5) *controllability and/or cure* – the individual's belief in themselves and health professionals to influence the condition (Fowler & Bass, 2006; Leventhal *et al.*, 1992). Research has demonstrated that there are important inter-relationships between each of these five components, suggesting that illness representations are best understood as groups of beliefs or schemata, rather than single cognitions (e.g. Moss-Morris, 1998; as cited in Vaughan *et al.*, 2003). Evidence suggests that certain illness representations are related to coping strategies and treatment adherence, including carrying out self care activities, and seeking appropriate medical help (Hampson *et al.*, 1990), along with other outcome variables such as functional activity and psychological well being (e.g. Moss-Morris *et al.*, 1996).

### **1.3.2.1      *Illness representations and their relation to adjustment in Multiple Sclerosis***

Relatively few studies have directly investigated the illness representations of PwMS, and their relation to outcome. Jopson and Moss-Morris (2003) used a well validated measure of illness perceptions, the Illness Perceptions Questionnaire-Revised (IPQ-R; Moss-Morris *et al.*, 2002), and found that illness representations played a significant role in individuals' adjustment to MS. The illness representations that appeared most associated with poorer outcomes involved attributing wide ranging symptoms to the disease itself, having low levels of perceived personal control over the disease, perception of severe consequences, believing it had a cyclical timeline, belief that psychological factors caused MS, and a lack of coherent understanding of MS (Dennison *et al.*, 2009). Jopson and Moss-Morris (2003) acknowledge various limitations of their study, including the cross sectional design making it impossible to discern the direction of relationships between variables. It is possible, for example, that individuals could become depressed for social reasons, and that depression could then cause changes in their illness representations. The authors suggest, given evidence for the addressing of negative cognitions alleviating depression, that the relationship between illness representations and mood is likely to be reciprocal. Contrary to the authors' assertion, however, the evidence base for the addressing of cognitions as alleviating depression is somewhat questionable (Longmore & Worrell, 2007; see later discussion in section 1.4.5.1). A relative strength of Jopson and Moss-Morris's (2003) study was that the analysis controlled for disease severity, which along with self reports included one objective measure.

A similar piece of cross sectional research carried out by Vaughan *et al.* (2003), using the Illness Perception Questionnaire (IPQ; Weinman *et al.*, 1996) and a variety of outcome measures, found that holding perceptions of a strong illness identity (i.e. attributing many symptoms to the condition), severe illness consequences, and low levels of control over the effects of disease tended to have the greatest number of relationships with poorer outcomes. Spain *et al.* (2007) also found illness perceptions



to correlate with health related QoL in a MS population. The ‘identity’, ‘consequences’ and ‘control/cure’ subscales of the IPQ tended to correlate with the greatest number of outcome measures.

### **1.3.2.2      *Other symptom related cognitions and their relation to adjustment in Multiple Sclerosis***

Various illness cognitions, other than stress appraisals and illness perceptions as already described, have been investigated in PwMS and other chronic health conditions.

#### ***Helplessness***

A study carried out by Shnek *et al.* (1997) found a positive correlation between perceptions of helplessness and symptoms of depression in PwMS, after controlling for possible confounding variables such as demographic factors and disease severity.

#### ***Benefit Finding***

Benefit finding is conceptualised as an adaptive process with individuals reporting a variety of benefits or gains from facing adversity, such as perceptions of personal growth, improvements in interpersonal relationships, or a change in priorities or goals. Pakenham (2005) investigated benefit finding in a MS population, using a longitudinal design. This study measured, among other factors, benefit finding (with subscales of ‘personal growth’ and ‘family relations growth’), along with positive and negative adjustment measures. After controlling for other variables, benefit finding was found to have strong direct effects on positive outcomes, but no direct effect on distress or subjective perceptions of health. Benefit finding also showed an association with lower levels of negative affect (Pakenham, 2005).

## Acceptance

While ‘acceptance’ of illness is widely believed to be beneficial for adjustment, relatively few studies have directly investigated this in a MS population. Harrison *et al.* (2004) found lower acceptance of disability to be associated with more negative impacts on the marital relationship over time. The operational definition of acceptance of disability used in this study was when individuals come to ‘believe their physical differences are part of who they are’ (p.272.).

More recently, Stuifbergen *et al.* (2008) investigated acceptance in relation to a variety of outcome measures while developing the 10-item ‘Acceptance of Chronic Health Conditions Scale’ (ACHCS). They used a large sample of 822 PwMS. It is important here, particularly in relation to later discussion (see chapter 1.4.3.1.), to note the definitions of acceptance used by Stuifbergen *et al.* (2008), which underpin their scale:

“Emotional acceptance involves the affective internalization of the functional implications of the impairment into the self-concept [emphasis added], as well as behavioural adaptation and social reintegration into the individual’s life” (pp.101-102.)

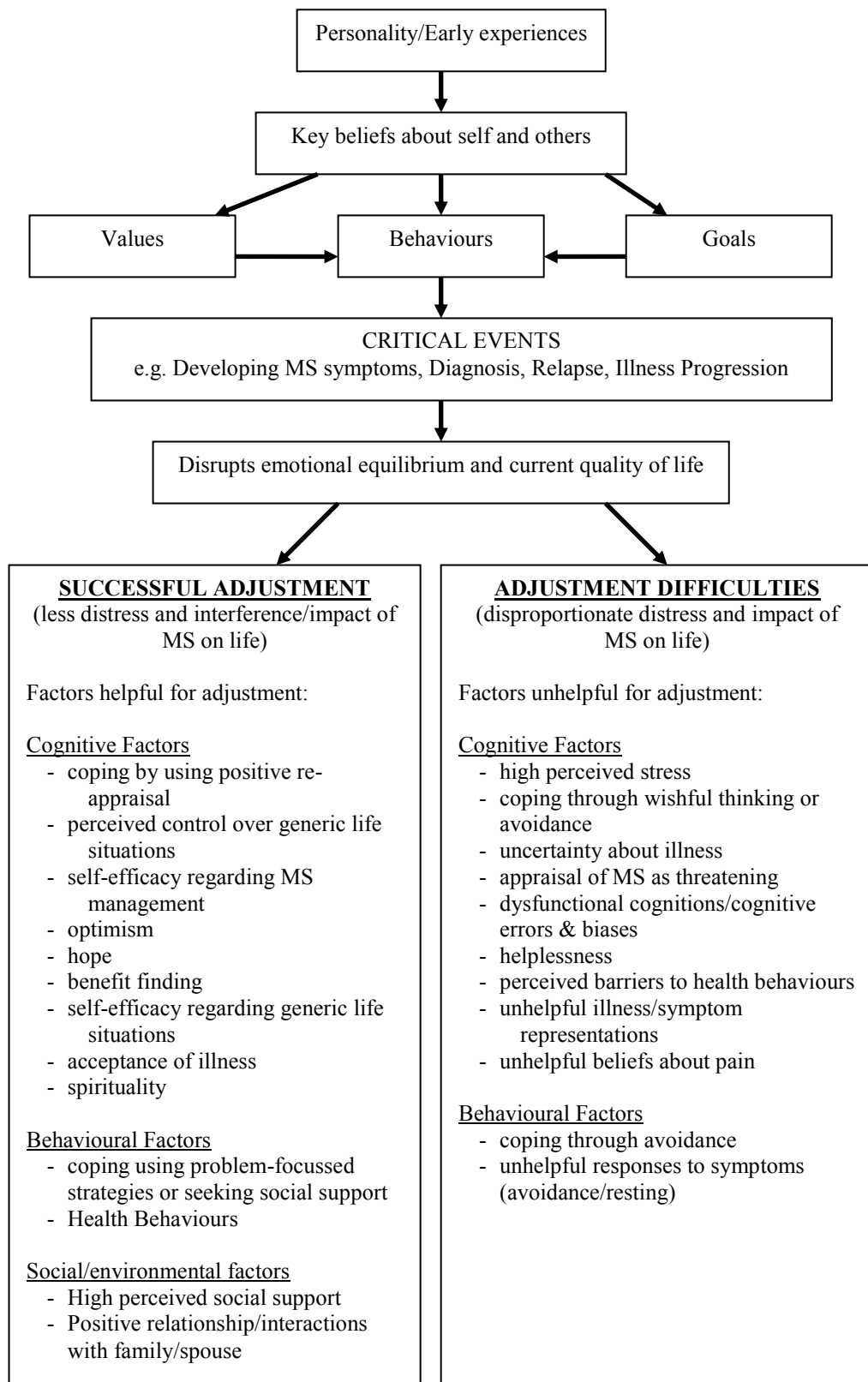
“Acceptance as defined here does not imply passive resignation to a hopeless situation of loss, but rather a *belief* [emphasis added] that one’s chronic condition has been integrated into the complexity of one’s life.”(p.103.)

The notion of a change in the self-concept and beliefs suggests that acceptance, by these definitions, involves a *change in cognitive content*. Higher scores on the ACHCS were found to correlate significantly with various outcome measures, including: higher perceived QoL, higher perceived health, and lower levels of depressive symptomatology.

### 1.3.3                    **Synthesis of research into the process of adjustment to MS**

The literature reviewed thus far illustrates that the SCM (Lazarus & Folkman, 1984) and the CSM (Leventhal *et al.*, 1984) have been highly influential models in how researchers have conceptualised the process of adjustment to chronic health conditions. The ways in which individuals appraise their symptoms, the challenges they face, and their ability to cope, appear to influence the quality of their adjustment. Perhaps the central concept is that the *content* of individuals' thoughts regarding their illness has a significant bearing on outcome, so are thus potentially viable targets for intervention.

Dennison *et al.* (2009) recently proposed a provisional 'working model of adjustment to MS'. Their model is largely based on Beck's (1976) cognitive model of emotional disorders, and also posits the psychological correlates of successful adjustment based on their review of the literature. The model proposed by Dennison *et al.* (2009) is represented diagrammatically in Figure 3 below. In line with Beck's original conception, the upper portion of the model illustrates how early experiences shape individuals' beliefs about themselves and others, which in turn influence how they relate to the world. Ongoing symptoms of MS constitute 'critical events' which disrupt individuals' emotional equilibrium, and impact upon their general well-being. The lower half of Figure 3 summarises the cognitive, behavioural, and social factors which Dennison *et al.* (2009) found, through their review of the literature, to have the greatest influence upon adjustment outcomes. Some of these factors (listed in the bottom half of Figure 3) have been covered in the preceding discussion, while others are beyond the scope of the current discussion.



**Figure 3: A working model of adjustment to Multiple Sclerosis**  
(reproduced from Dennison *et al.*, 2009).

The model proposed by Dennison *et al.* (2009) holds many commonalities with recent models of adjustment developed by other researchers (e.g. Sharpe & Curran, 2006; Walker *et al.*, 2004). Sharpe and Curran's (2006) model is also essentially based on Beck's (1976) model of emotional disorders, viewing the chronic illness as a stressor which disrupts emotional equilibrium. It affords illness representations quite a central focus, as adjustment is conceptualised as the process of individuals incorporating their illness representations into adaptive views of themselves and the world in order to facilitate active coping and positive health behaviours. The authors suggest that individuals may go through a 'hierarchical' series of re-appraisals in order to restore emotional equilibrium, starting with perhaps re-appraising the illness itself, or potentially progressing as far as attempts to change more core schema and goals if necessary.

Similarly, Walker *et al.* (2004) describe a 'biopsychosocial' model of adjustment to chronic illness, which is heavily influenced by Lazarus and Folkman's (1984) SCM. Their model also acknowledges that an individual's early experience and personality characteristics will tend to influence how they tend to appraise and cope with a health threat, which in turn will influence their affect and physical health.

The psychological correlates of adjustment to MS identified by Dennison *et al.* (2009) are consistent with the conclusions of De Ridder (2008) who reviewed the literature pertaining to adjustment to chronic illnesses. De Ridder identified four key cognitive and behavioural processes associated with positive adjustment, recommending that clients should 'remain as active as is reasonably possible, acknowledge and express their emotions in a way that allow them to take control of their lives, engage in self-management, and try to focus on potential positive outcomes of their illness' (De Ridder, 2008, p.1).

## **1.4 Acceptance and Commitment Therapy (ACT) and Mindfulness: ‘The Third Wave’ of behavioural therapy.**

The following discussion focuses on the underlying theory, and applications to date, of Acceptance and Commitment Therapy (ACT; Hayes *et al.*, 1999) and Mindfulness based approaches. These approaches are sometimes referred to as being part of the ‘third wave’ of behavioural therapies on the premise that the evolution of behaviour therapy can be separated into three generations: traditional behaviour therapy, CBT, and a third generation of more recent ‘contextualistic approaches’ (Hayes, 2004). The primary focus of the discussion will be on ACT, as it is most relevant to the current research, while mindfulness will also be afforded brief coverage as it has strong theoretical associations with ACT.

When the terms ‘CBT’, cognitive therapy (CT), or ‘traditional CBT’ are used in the following discussion, they will refer to Beckian (Beck *et al.*, 1979) approaches to treatment, which could be considered as part of the ‘second wave’ of behaviour therapy.

### **1.4.1 Philosophical underpinnings of ACT**

ACT is rooted in a pragmatic philosophy known as ‘functional contextualism’ (FC). Contextualism views the psychological events of an individual as ‘interacting in and with historically and situationally defined contexts’ (Hayes *et al.*, 2006, p.4). Put more simply, this standpoint suggests that no psychological or behavioural events should be considered in isolation, as their meanings are dependent on the context in which they occur. Hayes (1995) argues that from this perspective no psychological events (i.e. cognitions, emotions, behaviour) can be meaningfully described as *causing* one another directly, but only as influencing each other within certain contexts, giving the example of a spark only appearing to ‘cause’ an explosion in the context of other setting conditions such as oxygen and sufficient combustible

material being present. ACT theorists therefore aim to understand the functions of behavioural events within the full context in which they occur.

The specific goal of FC is stated as the prediction and influence of psychological events with precision, scope, and depth (e.g. Vilaradaga *et al.*, 2009). FC employs a ‘pragmatic truth criterion’ (Hayes, 1993). According to the pragmatic truth criterion, the degree to which analyses *work* in relation to specified goals is the degree to which those analyses should be considered ‘true’. If this philosophy is adhered to by ACT researchers with fidelity, then research and clinical practice are only judged by the extent to which they serve the goal of predicting and influencing psychological events with precision, scope, and depth, as opposed to their ‘truth’ in regards to any other objective reality. Hayes, Strosahl, Bunting *et al.* (2004) state that FC and the pragmatic truth criterion are not any more *correct* than other approaches, they are merely clear statements of the underlying assumptions adopted by researchers and practitioners.

This philosophy is reflected in ACT in a number of ways. Perhaps most notably for the current discussion, interventions are focused towards events that ACT proponents believe can be directly influenced. Hayes (1995) asserts that psychological events by definition cannot be directly influenced, because they are the dependent variables (DVs) of psychology; only Independent variables (IVs), the environment in the case of psychology, can be directly influenced. As Hayes *et al.* (2006) explain, from an ACT perspective ‘thoughts and feelings do not cause other actions, except as regulated by context’ (p.4). ACT, therefore, claims to have a *contextualistic* focus, seeking to change contexts that link psychological domains, rather than directly seeking to change their content (Hayes *et al.*, 1996).

#### **1.4.1.1      Potential Criticisms of ACT’s Underlying Philosophy**

ACT’s adoption of FC has drawn criticism from some quarters. In drawing comparisons between itself and other branches of mainstream psychology such as traditional behaviourism or CBT, ACT proponents (e.g. Hayes, 1995) have tended to accuse other approaches of ascribing to more mechanistic philosophies in

establishing causality between events (e.g. that a thought can *cause* a feeling or behaviour). It has been argued, however, that the dichotomies drawn between mechanistic and more contextualistic approaches may be somewhat illusory. Marr (1993) gives examples of how descriptions of mechanism are inherently contextual, as descriptions of component parts can only have any meaning when in relation to other elements, in the context of the wider system in which they exist. Thus, mechanistic accounts may already imply contextualism. Marr (1993) also suggests that the boundaries drawn between supposed DVs (i.e. psychological events) and the IV (i.e. the environment) by ACT researchers may be somewhat arbitrary, as these could be classified differently by different researchers. If the logic of ACT proponents is followed, a re-labelling of 'context' as a DV could render it immune to direct influence. It is also problematic that 'context' tends to be defined in somewhat vague fashion (Staddon, 1993) by ACT proponents, rendering discussion on the topic difficult to comprehend.

The adoption of FC is a statement of personal values on the part of a researcher, and represents a relativistic stance towards truth. Indeed, a functional contextualistic approach makes no claims to analysis being 'true' in relation to any objective reality. Ruiz and Roche (2007) suggest that there are risks in such a stance. Firstly, they suggest that distinctions between 'contextualists' and 'non-contextualists' may make it difficult to have effective or comprehensible dialogues regarding theoretical positions, research findings, and methodologies. Secondly, the pragmatic truth criterion may preclude wider discussion about the moral character of a given research program. Ruiz and Roche suggest that researchers ascribing to FC are effectively declaring themselves accountable only to their own personal moral values, rather than those of a wider society or scientific community (other than that of fellow ACT researchers). Ruiz and Roche raise concern that if research is carried out solely to meet personally held analytic goals, there may be potential risks of it serving researchers' own personal welfare, rather than that of wider society.

It is noteworthy that while FC makes very explicit reference to the importance of 'context', such consideration is surely not exclusive to ACT practitioners. Clinical



psychologists, including those who would describe themselves as primarily employing a CBT approach, commonly employ an inclusive and holistic approach to formulating the problems described by individuals, which surely involves consideration and manipulation of 'context'. ACT researchers stated aim to understand the functions of behavioural events in their full context sounds by no means unique. It is possible that statements of fundamental differences in philosophical underpinning between ACT and CBT may serve a purpose for ACT in appearing to differentiate itself from CBT, and give a seemingly strong and clearly formulated foundation, when differences between ACT and CBT at the level of applied research and clinical practice are more limited. If this is indeed the case, it would render the underpinning of FC somewhat superfluous in terms of real influence on research and practice.

Finally, ACT's philosophical underpinnings are drawn upon in the rationale for excluding cognitive restructuring from treatment (see later discussion in section 1.4.5), asserting that cognitions cannot be directly influenced, because they are DVs. The basis for this claim appears somewhat unclear. While perhaps cognitions cannot literally be influenced directly, it is possible that relatively direct methods (e.g. offering evidence that strongly and directly contradicts an assumption) could have a sudden and modifying influence on cognitive content. Labelling cognitions as a DV, and thus immune to direct influence, may be a somewhat convenient or even pedantic use of philosophical underpinning to support ACT practice.

While ACT's adoption of FC as an underlying philosophy may carry potential difficulties, there is perhaps some merit in clearly stating the goals and assumptions on which any scientific endeavour is based, so these assumptions can be clearly understood and debated. An awareness of FC may also make the rationale for some of the supposedly unique features of ACT somewhat clearer (Hayes, Strosahl, Bunting *et al.*, 2004).

### 1.4.2 Relational Frame Theory

Relational Frame Theory (RFT; Hayes *et al.*, 2001) is a modern behavioural account of human language and cognition. The RFT research programme is widely regarded as being particularly complex and difficult to grasp (e.g. Gross & Fox, 2009; Palmer, 2004).

As described by Hayes *et al.* (2006): ‘According to RFT, the core of human language and cognition is the learned and contextually controlled ability to arbitrarily relate events mutually and in combination, and to change the functions of specific events based on their relations to others.’ (p.5) One commonly cited (e.g. Hayes *et al.*, 2006) example of these principles is how children in the United States (US) come to understand the relative values of coinage. The example is outlined here with the use of British coinage. Young children will know that in a physical sense a two pence coin (2p) is bigger than a five pence coin (5p), this is known as a non-arbitrary relation. Children will later learn that 5p is bigger than 2p by social attribution (an arbitrary relation). This arbitrary relation is *mutual* (i.e. if 5p is bigger than 2p, then 2p is smaller than 5p), *combinatorial* (i.e. if 20p is bigger than 5p, and 5p is bigger than 2p, then 20p is bigger than 2p) and *alters the function of related events* (i.e. if 5p was used to buy sweets, 20p would subsequently be preferred even though it hadn’t used for this purpose before). The *transformation of stimulus functions* is highly significant for RFT and ACT, as it indicates that stimuli can acquire behavioural functions based solely on their participation in verbal relations with other events (Gross & Fox, 2009) rather than through direct experience.

Hayes *et al.* (2001) argue the primary implications of RFT in the area of psychopathology are that: (1) some of the processes of verbal learning and problem solving can also lead to psychopathology, (2) learning is additive and cannot readily be undone, (3) attempts to directly change specific aspects of a cognitive network may have the unintended effect of elaborating it, (4) contextual features control the impact of cognitive networks, so it should be possible to reduce their impact without

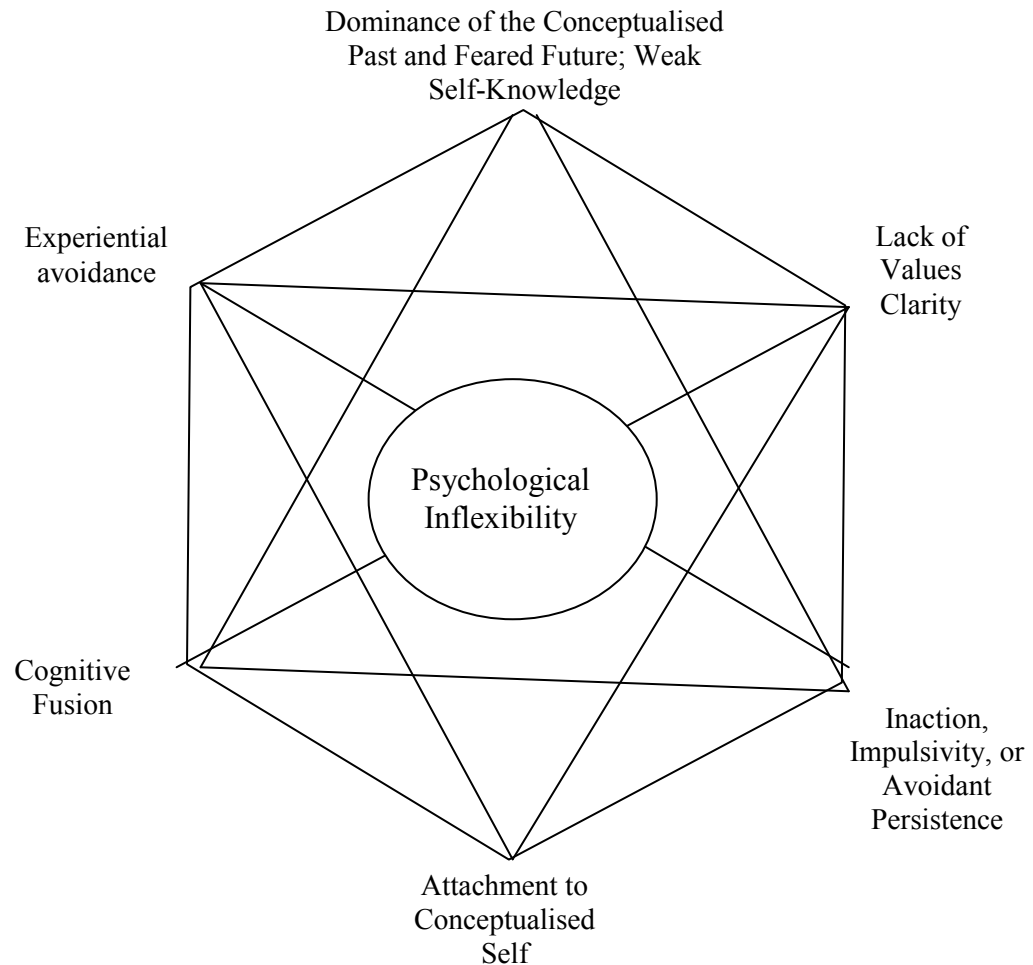
changing their form (Hayes *et al.*, 2006), by manipulating the *context*. Hayes, Masuda *et al.* (2004) describe such problematic contexts as including ‘those in which private events need to be controlled, explained, believed, or disbelieved, rather than being experienced.’ (p.5)

RFT has created intense debate within the field of behaviour therapy. One review, for example, described RFT theorising as unintelligible, ambiguous and contradictory (Burgos, 2003). The debate over RFT is highly technical and has spanned many years, but was recently summarised by Gross and Fox (2009). One criticism (Osborne, 2003) is that RFT is not truly ‘post-Skinnerian’ as it relies on many of the same fundamental principles of Skinner’s account (e.g. that relational responding is the result of differential reinforcement), though these principles are fully credited by Hayes *et al.* (2001). It has variously been suggested that RFT does not offer a new behavioural principle or theory, as relational framing can be accounted for by a complex chain of other existing behavioural principles (Burgos, 2003; Malott, 2003; Salzinger, 2003). Palmer (2004) criticised RFT for theoretical confusion over whether relational frames are part of the history that bring about behaviour (a process), or a class of behaviour themselves (an outcome). These criticisms, among others, have been countered (Hayes *et al.*, 2003; Hayes & Barnes-Holmes, 2004) by the authors of RFT in depth which is beyond the scope of the current discussion. Proponents of RFT argue that it does offer new behavioural principles at the level of process and outcome.

#### **1.4.3 An ACT conceptualisation of Psychopathology: Psychological Inflexibility and the ACT hexaflex**

On the basis of RFT, ACT views psychopathology as primarily being the result of ‘psychological inflexibility’, which can be defined as ‘the way that language and cognition interact with direct contingencies to produce an inability to persist or change behaviour in the service of long-term valued ends’ (Hayes *et al.*, 2006, p.6). Put more simply, the way in which an individual relates to their internal mental experiences can hinder their ability to engage in valued living. An ACT model of

psychological inflexibility can be seen below in figure 4, which consists of six theoretically overlapping concepts.

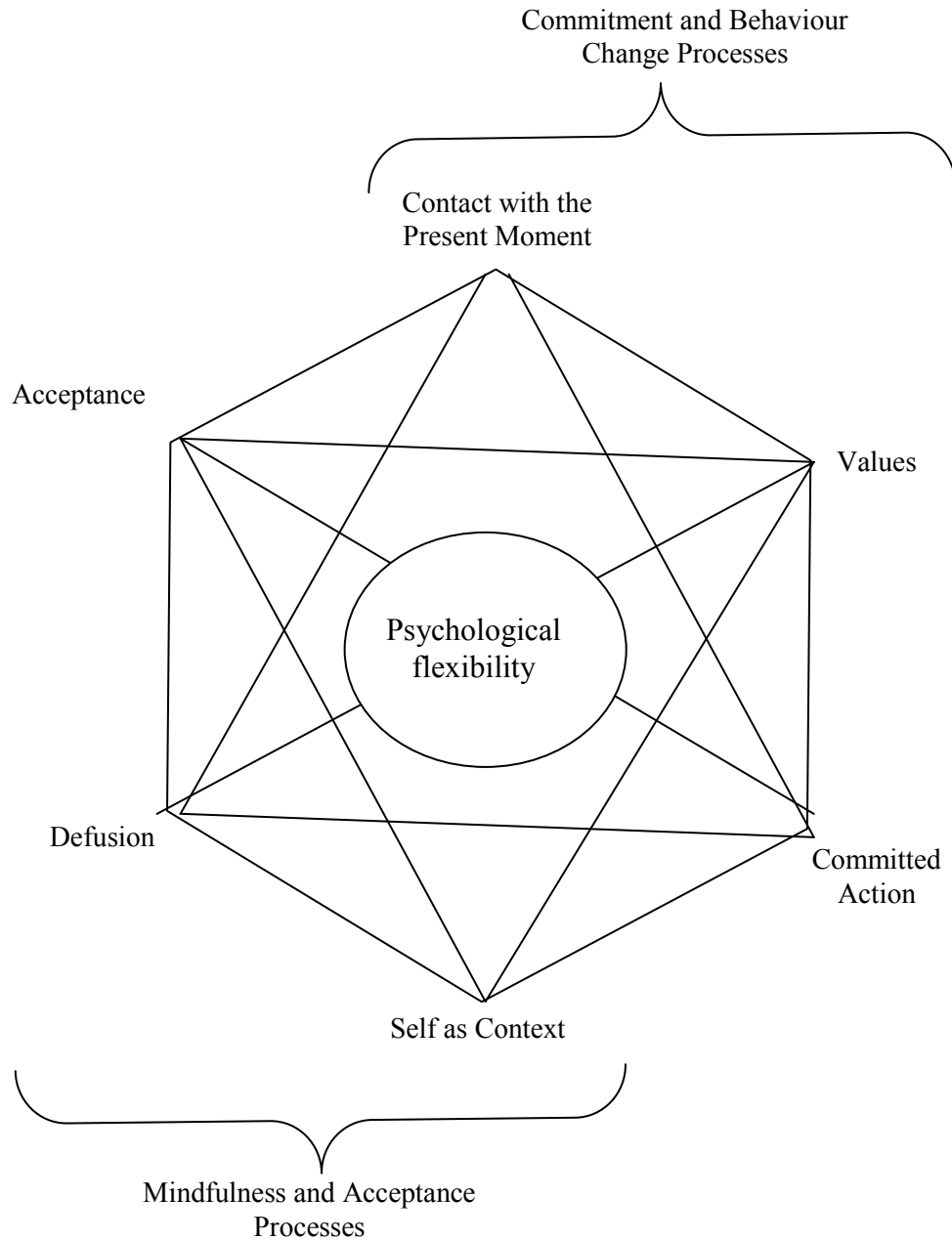


**Figure 4: An ACT/RFT model of psychopathology**  
(reproduced from Hayes *et al.*, 2006)

Cognitive fusion refers to the tendency for individuals to become fused with or excessively ‘caught up’ in their thoughts, so thoughts have an unduly strong influence over behaviour (Hayes *et al.*, 1999). Experiential avoidance is the attempt to alter the form or frequency of private events, even if this requires engaging in undesired or maladaptive behaviours (Hayes *et al.*, 1996). Dominance of the conceptualised past and feared future and attachment to the conceptualised self are closely related to cognitive fusion, as they refer to the tendency to become fused with verbally based conceptualisations of the past, future, and the self. Lack of values clarity, and inaction and impulsivity are the more overt behavioural manifestations of

psychological inflexibility, whereby the individual becomes less engaged in valued living.

These six processes of psychopathology can be contrasted with the six more positive psychological processes which ACT seeks to strengthen, as summarised in Figure 5 below. The processes in Figure 5 are effectively the opposite of those in Figure 4. The processes in Figure 5 are each described briefly below.



**Figure 5:** A model of the positive psychological processes ACT seeks to strengthen (reproduced from Hayes *et al.*, 2006)

#### 1.4.3.1 **Acceptance**

‘Acceptance involves the active and aware embrace of those private events occasioned by one’s history without unnecessary attempts to change their frequency

or form’ (Hayes *et al.*, 2006, p.7). The word ‘willingness’ is sometimes used interchangeably with ‘acceptance’ in ACT, since acceptance from an ACT perspective is a willingness to experience difficult thoughts and feelings in the course of behaving consistently with ones values. It is important to note that an ACT definition of acceptance differs from other conceptualisations used in adjustment literature, such as the definitions of Stuijbergen *et al.* (2008) quoted earlier (see section 1.3.2.2.). Such definitions of acceptance require a change in the *content* of thought, while in ACT, acceptance involves change in how individuals *relate* to their experiences, and in what behaviours then become possible through that change in the context of relating to private events.

#### **1.4.3.2 Cognitive Defusion**

Defusion techniques aim to alter the undesirable functions of thoughts, reducing their literal quality, as opposed to attempting to change their content (Hayes *et al.*, 2006). Thus rather than a thought (e.g. “I am no good”) being taken as literally true, it may be experienced more objectively as a thought (i.e. “I am having the thought that I am no good”). Defusion techniques tend to reduce the believability, or attachment to, private events rather than necessarily changing their form or frequency. Defusion techniques aim to reduce the capacity of unwanted private events to regulate or control behaviour.

#### **1.4.3.3 Being Present**

ACT encourages ‘ongoing contact with psychological and environmental events as they occur’ (Hayes *et al.*, 2006, p.9), so individuals are more able to react flexibly to contingencies in a way that is consistent with their values (Hayes *et al.*, 2006).



#### **1.4.3.4. Self as context**

ACT utilises perspective taking exercises that encourage contact with a transcendent sense of self, or self as context. Such exercises aim to help clients ‘distinguish between the content of consciousness and the person as a perspective-taking context for that content, in the hopes that this will reduce attachment to the conceptualized self’ (Hayes *et al.*, 2011, p.156).

#### **1.4.3.5 Values**

‘Values are chosen qualities of purposive action’ (Hayes *et al.*, 2006, p.9). In ACT, values are described as directions in which to live (rather than ‘goals’), so can never be fully finished or attained. For example, one could never ‘finish’ being a good parent, if that is a chosen value.

#### **1.4.3.6 Committed Action**

ACT encourages individuals to develop wide patterns of behaviour in relation to chosen values (Hayes *et al.*, 2006). Committed action can involve the establishment of short, medium and long-term goals in relation to chosen values.

#### **1.4.3.7. The Goal of ACT: Psychological Flexibility**

The six ACT processes all serve to promote psychological flexibility, which Hayes *et al.* (2006) define as ‘the process of contacting the present moment fully as a conscious human being and persisting or changing behavior in the service of chosen values’ (p.9). The six core ACT processes are overlapping and interrelated. While initiating behaviour change in the pursuit of chosen values will often bring clients

into contact with perceived difficulties and obstacles, other ACT processes (i.e. acceptance, defusion etc.) are intended to help individuals address these.

#### **1.4.4 Mindfulness**

Mindfulness is typically an important element of interventions in ACT and other ‘third wave’ therapies. The practice of mindfulness has evolved from various meditation techniques utilised in Buddhist meditation practice (Hanh, 1976; as cited in Bishop, 2004). Mindfulness has been defined in various ways by different authors. For example, Kabat-Zinn (2003) defines mindfulness as ‘the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding experience moment by moment.’ (p.145). Fletcher and Hayes (2005) suggest that mindfulness can be usefully defined from an ACT/RFT perspective as being ‘the defused, accepting, open contact with the present moment and the private events it contains as a conscious human being experientially distinct from the content being noticed.’ (p.322.), effectively defining mindfulness as being comprised of the four ACT process relating to private events (as illustrated in Figure 5).

#### **1.4.5 Current debate between traditional CBT and the ‘third wave’ therapies**

The emergence of the ‘third wave therapies’ has produced intense debate between its proponents, and researchers with an orientation towards more traditional CBT. The following summary of the debate will adopt a structure similar to that adopted by Arch and Craske (2008) who outlined the main dichotomies in terms of underlying theory and practice that currently pervade the debate.

#### **1.4.5.1      *Mediators of therapeutic change: CBT mechanisms vs. ACT mechanisms***

For any therapy, it is often supposed that the components of that therapy are responsible for therapeutic gains demonstrated. While ACT and Mindfulness supposedly work by enabling individuals to change the way they *relate to* their thoughts and emotions, CBT purports to change cognitive *content* to impact upon emotional experiences (Beck, 1993). These assertions can be tested by certain study designs, such as component analyses (testing the different components of a treatment against each other) and mediational analyses (testing whether the posited processes of a given therapy mediate the outcome).

#### ***Evidence for mechanisms of CBT as mediating therapeutic change***

Jacobson *et al.* (1996) conducted the first component analysis of CBT in the treatment of depression. They compared CBT with two other conditions representing its component parts: a ‘behavioural activation’ condition, and an ‘automatic thoughts’ condition (which included all elements of the behavioural activation condition, with the addition of negative automatic thought modification). This study had various strengths to its methodology (Longmore & Worrell, 2007). In each condition, treatment was provided by four experienced therapists. A year was devoted to piloting treatment conditions, and writing detailed manuals for each condition. A sample of sessions were taped and listened to by a rater (who was blind to the treatment condition) to monitor treatment adherence. Surprisingly perhaps, no significant differences were found in levels of depressive symptomatology between the three conditions, either immediately post treatment, or at 6-month follow-up. The authors acknowledge that this result was obtained despite their expectancy that the full CBT condition would be the most effective treatment. The authors concluded that the results raised questions over the mechanisms of change proposed by Beckian CBT (Jacobson *et al.*, 1996). This study did have some minor limitations, such as the

descriptions of treatment conditions being relatively broad. It could be argued that the behavioural activation condition had some cognitive elements, such as the imaginal rehearsal of activities. Also, elements of treatment were added in a sequential manner (i.e. the full CBT condition started with behavioural activation and added cognitive elements later in treatment), so it could be argued the elements added last could be expected to add the least benefit (if behavioural and cognitive interventions act on related mechanisms). The findings of this study were later replicated by the same research group (Dimidjian *et al.*, 2006) with a large sample ( $N = 241$ ). Full CBT was found to be no more effective than a simpler behavioural activation (BA) condition, and BA was even found to be more effective than full CBT for the most severely depressed clients.

Studies investigating the cognitive mediators of therapeutic change have also found surprisingly little evidence to support the Beckian Cognitive model. Jacobson *et al.* (1996) issued participants with the Automatic Thoughts Questionnaire (ATQ; Hollon & Kendall, 1980) and the Expanded Attributional Style Questionnaire (EASQ; Peterson & Villanova, 1988) to investigate whether changes in cognitive content mediated outcomes. No such relationship was found. A meta-analysis conducted by Oei and Free (1995) investigated the link between change in cognitions and change in symptoms of depression between different forms of therapy (different psychological and pharmacological therapies). It was found that changes in cognitive style occurred across all active therapy, not just CBT.

A review (Longmore & Worrell, 2007) of thirteen CBT component analyses, and evidence for the mediating effect of cognitive change on outcomes, concluded that there is 'a worrying lack of empirical support for some of the fundamental tenets of CBT.' (p.185.) and that the need to challenge or modify the content of thought in CBT is largely unsupported.

There is, however, some evidence of cognitive change mechanisms mediating the effects of CT. DeRubeis *et al.* (1990) compared two groups of participants suffering from major depressive disorder: one receiving CT, and the other receiving

pharmacotherapy alone. It was found that scores on measures of cognitive content at mid-treatment did predict changes in depression between mid-treatment and post-treatment in the group receiving CT, but not in the pharmacotherapy alone group.

Hofmann (2008) contends that Longmore and Worrell's (2007) review of the literature reaches biased and mistaken conclusions regarding the evidence for cognitive changes mediating symptom change. Hofmann argues that cognition can mediate change through other means than Beckian cognitive challenge alone, giving the example of behavioural strategies such as exposure potentially altering cognitive content (e.g. fear expectancy). Such a line of argument is difficult to dispute, as it becomes impossible to isolate cognitive change techniques for study (i.e. if a behavioural intervention becomes a *cognitive* technique). Hofmann (2008) also suggests that the test for mediation is more complex than authors often realise, that the appropriate statistical tests have only recently been suggested, and that recommended methodologies for detecting a mediational relationship (Kraemer *et al.*, 2002) are very rarely employed, such as measures being administered at appropriate time points.

### *Evidence for mechanisms of ACT as mediating therapeutic change*

The study of mediating variables has been far more common in ACT outcome studies. Hayes *et al.* (2011) state that of all RCTs of ACT, around two thirds have published mediational analyses, and across these 'about 50 per cent of the between-group differences in follow-up outcomes can be accounted for by the mediating role of differential post levels in psychological flexibility and its components' (p.157). Only a small selection of these studies can be reviewed here.

One technique used in ACT to measure cognitive defusion has been to use existing CBT process measures, such as the Dysfunctional Attitude Scale (DAS; Weissman, 1979) or ATQ, but to ask participants to make an additional rating on how *believable* they find the given thought. Hayes *et al.* (2006) conducted a reanalysis of data from the first RCT on ACT (Zettle & Hayes, 1986). The original article had compared an

early version of ACT with CT among depressed clients, delivered in a 12-week individual protocol. ACT was found to be superior to CT on depression outcome post treatment and at 2-month follow-up. The two groups did not differ on their scores on the ATQ, a measure of depressogenic thought frequency, but they did differ for scores on how believable they found the thoughts when they were occurring, with the ACT group finding the thoughts less believable. The reanalysis conducted by Hayes *et al.* (2006) found that the believability of depressogenic thought mid-treatment mediated the superior outcomes in ACT achieved in this study. Similar findings were produced by Zettle *et al.* (2011), who conducted a reanalysis of the second RCT in ACT (Zettle & Rains, 1989), which compared 12-week group programmes of CT and ACT with depressed clients. At two month follow-up, the differential impact of ACT versus CBT (in favour of ACT) on symptoms of depression was mediated by differential levels of the *believability* of thoughts (using the DAS) as measured post intervention, rather than the level of dysfunctional attitudes or occurrence of depressive thoughts. Scores on the DAS did not mediate outcomes for the CBT condition, and CBT did not change scores on the DAS any more so than ACT. These reanalyses are notable, as they are two of the very few studies which have compared ACT and CBT directly, and provide evidence for mediating variables for both treatment conditions. Similarly, in a study investigating ACT for psychosis, Gaudiano *et al.* (2010) found that the differential benefits of ACT on hallucination related distress were mediated by differential post intervention levels of the *believability* of the hallucinations, and not their frequency.

In a review of the literature, Hayes *et al.* (2006) cite evidence for the mediating effects of ACT variables in positive treatment outcomes for many other conditions including: smoking cessation, coping with end stage cancer, frequency of seizures in epilepsy, distress experienced in chronic pain, and social phobia. It is worth noting, however, that a few of these studies tended to cite the Baron and Kenny (1986) criteria for testing mediating variables, rather than more rigorous modern methods (Kraemer *et al.*, 2002), which require more complex design and statistical tests (Hofmann, 2008; Preacher & Hayes, 2008). Also, ACT measures have sometimes been developed for assessment or tracking individual change, and therefore lack the

robust demonstration of psychometric properties that would give greater confidence in their use in research. The Acceptance and Action Questionnaire (AAQ; Hayes, Strosahl, Wilson *et al.*, 2004) and Acceptance and Action Questionnaire II (AAQ-II; Bond *et al.*, in press) are, however, particularly well validated ACT process measures.

#### **1.4.5.2      *Treatment of thoughts: Cognitive restructuring vs. Cognitive defusion***

While traditional CBT focuses on restructuring or modifying the content of thought, ACT favours an approach encouraging cognitive defusion and acceptance.

ACT proponents argue (e.g. Hayes *et al.*, 2006) that a focus on changing the content of thought can have the paradoxical effect of making a thought more salient and distressing. Research on the effect of thought suppression (e.g. Wegner, 1994) has been cited to support this assertion, suggesting that the approach of CBT can encourage avoidance and suppression of thought (Hayes *et al.*, 1999). This has been strongly disputed by proponents of traditional CBT. For example, Leahy (2008) describes the notion that the challenging of thought may be deleterious to clients as ‘a remarkable and alarming claim—one that has absolutely no basis in reality.’ (p.149) Experimental studies conducted by Gross (2002) have used ‘cognitive reframing’ as a comparison condition to suppression, and found that such cognitive reframing does not produce the same outcomes as suppression, but rather tends to have a positive effect in reducing the intensity and behavioural expression of negative emotion.

Arch and Craske (2008) highlight that CBT and ACT approaches to cognition are similar in some ways, including encouraging clients to face previously avoided experiences. They speculate that both cognitive restructuring and defusion may operate through similar mechanisms based on exposure, and that cognitive restructuring may be similar to defusion, in that clients are encouraged to gain some distance from their thoughts. This similarity has been observed by other CBT

proponents. Leahy (2008), for example, suggested that CBT already includes defusion, but refers to it as ‘distancing’. An important distinction, however, is that ‘distancing’ in CBT is encouraged only as a first step towards the goal of changing the content of thought to make it less distorted and more realistic (Beck *et al.*, 1979), while defusion does not involve changing cognitive content. The results of mediational analyses, such as those described earlier (e.g. Zettle *et al.*, 2011) do however support the assertion that defusion (as measured by the believability of thought) is an active and distinct treatment component in ACT, and that it is differentially active in ACT compared to CBT.

It is worth noting that ACT techniques cannot entirely avoid contact with, or evaluation of, the content of thought. Arch and Craske (2008) suggest that for individuals to know which thoughts to defuse from, some initial appraisal of thoughts must take place, and that thinking is therefore paradoxically required as a first step in avoiding getting tied up in thought.

Experimental paradigms may be helpful in distinguishing the mechanisms and differential effectiveness of cognitive restructuring and defusion. Such research could include measuring behavioural avoidance and physiological reactivity rather than relying exclusively on self report measures (Arch & Craske, 2008), for example comparing physiological reactivity under an ‘exposure with cognitive restructuring’ condition versus ‘exposure with cognitive defusion techniques’.

#### **1.4.5.3      *Approach to emotional symptoms: Prediction and control vs. acceptance***

CBT has as one of its goals the prediction and control of emotional symptoms, while ACT advocates acceptance, which involves giving up the battle to control symptoms and instead to focus on behavioural goals, in the service of values, in the presence of unpleasant private events. In line with a CBT approach, there is evidence to suggest that perceptions of control over internal states and external events are predictive of positive coping and mental health (Skinner, 1995), even if control over these factors



is actually very limited. Acceptance techniques may, however, also promote clients' sense of mastery and control over symptoms, though this is not ACT's explicit intention. Similarly, acceptance related techniques such as mindfulness may serve to increase clients' perceptions of predictability of symptoms, by increasing awareness of their own internal state and current environment (Arch & Craske, 2008).

CBT may also contain elements that could readily be seen as consistent with an ACT consideration of emotional symptoms. Research into exposure therapy (e.g. Craske *et al.*, 2008), has found that actual reduction in emotional distress is not predictive of overall outcome, but rather exposure may be best understood as increasing individuals' ability to interact with feared stimuli without the usual effects on behaviour (i.e. escape or avoidance).

Hofmann and Asmundson (2008) suggest that Gross' (2002) process model of emotions provides a useful way to differentiate CBT and ACT's treatments of emotions. They suggest that while ACT focuses on *response-focussed* emotion regulation strategies, undermining clients' experiential avoidance once an emotional response has been initiated, CBT adopts a more *antecedent-focussed* approach to emotional regulation, encouraging strategies such as the modification of situations and attentional focus, and reappraisals of emotional triggers before an emotional response is fully activated. It may, however, be overly simplistic of Hofmann and Asmundson to suggest that the techniques of CBT and ACT can be so neatly dichotomised in this way. Such a stance forgets the strong behavioural and pragmatic element of ACT interventions, and hence the possibility that the implementation of values consistent patterns of effective action may well include pro-active behaviours that could be termed 'antecedent-focussed'. Conversely, it seems surprising that many CBT therapists would claim to be entirely antecedent focussed. CBT surely purports to help clients learn to cope with difficult emotions which have been initiated, rather than solely anticipate them so effectively, in an 'antecedent-focussed' fashion, that emotional response can be circumvented.

#### **1.4.5.4      *Therapeutic goals: Symptom reduction vs. valued living***

While CBT has symptom reduction as one of its primary goals, ACT focuses on clients engaging in more valued living. ACT practitioners tend not to focus explicitly on symptom reduction, but rather acknowledge it as a possible bi-product of relating to their experiences more flexibly and increasingly engaging in valued living (Harris, 2009). Arch and Craske (2008) provide a discussion of this difference in therapeutic goals between the two approaches, and suggest the apparent dichotomy may not be so clear. While ACT targets valued living very explicitly, clients may also move towards valued living through CBT techniques such as exposure and behavioural activation. Behavioural activation may often involve taking committed action toward living in valued directions. Conversely in ACT, pursuit of valued living may lead to behavioural exposures and hence to reduction in symptoms.

Arch and Craske (2008) speculate that there may be two pathways through which symptom reduction and valued living may mediate outcomes in therapy. Firstly, symptom reduction and control may mediate increases in values congruent activity, and secondly, values congruent activity may increase perceptions of control and diminish symptoms through exposure. If such pathways are indeed in operation, future research could possibly elucidate whether they are differentially active in ACT and CBT (Arch & Craske, 2008).

#### **1.4.5.6      *Summary of ACT vs. CBT debate***

While there are a number of apparent dichotomies between CBT and ACT, a more thorough analysis suggests that there is, of course, overlap at the level of both theory and therapeutic technique between the two approaches (Arch & Craske, 2008). In light of the similarities between different psychotherapies (Wampold, 2007; as cited in DiGiuseppe, 2008), this is somewhat unsurprising. Hayes (2008) acknowledges

that there are areas of overlap between ACT and not only CBT, but also humanistic, existential, and analytic traditions as well.

On reviewing the dialogue between ACT and CBT, it is striking that proponents of CBT repeatedly use observations of theoretical overlap to make statements intended to subsume ACT under the CBT moniker. For example, Hofmann and Asmundson (2008) state that ‘Acceptance strategies intended to counteract suppression (experiential avoidance) are simply another tool in the arsenal of the CBT therapist to combat emotional disorders. Although acceptance strategies are not routinely used in CBT, they are certainly compatible with the CBT model and have almost certainly been employed by experienced therapists in certain cases.’ (p.13) In opposition to this, it should be borne in mind that mediational analyses (e.g. Zettle *et al.*, 2011) of CBT and ACT do appear to give preliminary support for the mechanisms of action being different between the two approaches, and ACT being effective due to the mechanisms it proposes. While Longmore and Worrell’s (2007) critique of CBT mediation studies was perhaps somewhat overstated, it does appear that the evidence base for the mediating effect of ACT constructs may be more compelling than that for CBT, despite the therapy’s comparatively recent evolution.

CBT proponents appear to be shifting the underlying theory of their approach in directions more consistent with ‘third wave’ approaches, such as Arch and Craske (2008) changing the definition of exposure to one based on increasing ‘emotional tolerance’. Hayes (2008) argues that CBT’s attempts to incorporate ACT theory and practice are illustrative of the paradigm’s loose theoretical underpinning. Hayes goes as far as to argue that in opposing the development of ACT as a therapeutic approach, CBT has come to behave more as a ‘tribe’ than a theory. Influential CBT researchers’ (e.g. Hofmann, 2008; Leahy, 2008) attempts to argue that CBT already does all that ACT does, or that it can readily incorporate ACT techniques without any inconsistency in underlying theory, do not appear particularly credible, and give

the impression of unconditionally defending the dominant paradigm (Moran, 2008), while introducing further confusion over what CBT actually is (Hayes, 2008).

Perhaps in an effort to defuse some of the tension between CBT and ACT, Hayes *et al.* (2011) have recently suggested that the term ‘third wave’ should perhaps be abandoned, as the implication of their superseding CBT has created conflict and tension. The authors suggest that the therapies previously referred to as ‘third wave’ should instead be termed ‘contextual CBT’, describing itself as ‘a distinguishable and emerging strand of thinking within CBT that has produced emerging consensus regarding the key variables in psychopathology and psychotherapeutic change.’ (p.162)

Further research is undoubtedly necessary to further elucidate the mechanisms of change in each therapy, whether they target the same or different paths to psychopathology (DiGiuseppe, 2008), and shed light on the primary question: under what circumstances should therapy focus on the form of thought and emotion, or on how individuals relate to their experiences?

#### **1.4.6 The evidence base for ACT**

##### **1.4.6.1 Summary of meta-analyses and reviews of ACT**

The following discussion of ACT outcomes will focus on the small number of reviews and meta-analyses of ACT outcome studies which have been carried out (Hayes *et al.*, 2006; Ost, 2008; Powers *et al.*, 2009; Ruiz, 2010).

Hayes *et al.* (2006) carried out a review of 21 RCTs, which varied greatly in the target problems they addressed. By targeting the most clinically relevant outcome variables for analysis, and weighting the average effect sizes by the number of

participants who produce that effect, the authors found that ACT produced moderate between condition effect sizes (Cohen's  $d$ ), of 0.66 at post ( $N = 704$ ) and follow-up ( $N = 519$ ). The studies varied in what comparison/control condition was used. Further analysis showed that when ACT was compared to waiting list, placebo, or general treatment as usual (TAU) it was found to be superior with effect sizes of  $d = 0.99$  post treatment and  $d = 0.71$  at follow-up, and ACT's performance was also superior in comparison to structured interventions designed to impact the problem, with effect sizes of  $d = 0.48$  post-treatment, and  $d = 0.63$  at follow-up. In their analysis of the small number of articles directly comparing ACT with traditional CT or CBT, the authors found between condition effect sizes of  $d = 0.73$  at post and  $d = 0.83$  at follow-up in favour of ACT. While acknowledging that larger scale studies were necessary, Hayes *et al.* (2006) concluded that ACT may have superior outcomes to CBT. While the conclusions of this meta-analysis were highly positive regarding ACT's effectiveness, it was conducted by the founder of ACT, Steven Hayes, and his colleagues, so therapy allegiance effects may be operating.

A more critical analysis was later carried out by Ost (2008). Thirteen ACT RCTs met Ost's inclusion criteria for analysis. In addition to meta-analytically assessing their efficacy, studies' methodologies were also reviewed. Methodological quality was rated on a 22-item scale, based on one used previously by Tolin (1999; as cited in Ost, 2008). As well as rating each ACT study on this scale, Ost took the unusual step (Guadino, 2009) of matching each ACT study with a "twin" CBT study published in the same journal of the same year, so the CBT studies could also be rated and compared with their ACT counterparts. If no such appropriate twin study existed, a comparison study was selected from one of three major outlets for CBT research (Journal of Consulting and Clinical Psychology, Behavior Therapy, or Behaviour Research and Therapy).

In terms of effect sizes, Ost's results were similar to those of Hayes *et al.* (2006). Overall, Ost found ACT to yield a mean effect size of  $d = 0.68$  (compared to Hayes *et al.*'s  $d = 0.66$ ). More detailed analysis showed effect sizes of:  $d = 0.96$  versus no treatment control condition,  $d = 0.79$  versus treatment as usual, and  $d = 0.53$  versus

active treatments, all in favour of ACT. On the methodology rating scale, however, ACT studies were found to have ‘significantly lower means than CBT-studies on the following items: Representativeness of the sample, Reliability of the diagnosis, Reliability and validity of outcome measures, Assignment to treatments, Number of therapists, Therapist training/experience, Checks for treatment adherence, and Control of concomitant treatments.’ (Ost, 2009, p.1) Primarily on the basis of the studies’ methodological weaknesses, Ost concluded that ACT did not meet criteria to qualify as an empirically supported treatment (EST; Chambless *et al.*, 1998). Ost made numerous recommendations on how the methodologies of ACT studies could be improved in future, along with suggesting that an appropriate focus for future research would be to compare ACT directly with CBT for the most common psychiatric disorders (i.e. anxiety disorders, depression, eating disorders).

Guadiano (2009) responded to Ost’s meta-analysis by arguing that comparing ACT and CBT studies was akin to comparing ‘apples and oranges’. Guadiano argued that ACT is at a far earlier stage of development compared to CBT, so studies are smaller scale and less funded, so cannot yet employ the same rigorous designs as CBT studies. He also pointed out that the ACT studies covered a diverse range of presenting problems (including psychosis, addiction, and personality disorder) while, the CBT ‘twin’ studies were limited to depression and anxiety disorders. The populations targeted in these ACT interventions are often more treatment resistant, and study designs are selected to be practicable in whatever context the research is taking place, so comparisons with selected CBT studies are perhaps unfair. Guadiano analysed the grant funding received by the ACT and CBT studies included in Ost’s analysis, and concluded that there were statistically significant ( $Z = 2.64, p = 0.008$ ) differences between them, with ACT studies receiving an average of \$111,428 each, and CBT studies receiving \$495,242. Guadiano argued that differences in the stage of development of the therapies, research aims, and quantity of grant funding, could account for the methodological differences found by Ost between ACT and CBT studies.

In reply to Guadiano, Ost (2009) argued that ACT's being at an earlier stage of development as a therapy may not necessarily account for the use of less rigorous or sophisticated study designs, and that researchers should still aspire to using the most advanced techniques for evaluating outcome research that CBT has developed over the past decades, irrespective of the disorder being studied. He also argued that differences in research grant funding can only really be argued to be responsible for perhaps two methodological variables ('reliability of diagnosis' and 'checks for treatment adherence') where ACT scored lower than CBT, while the remaining six variables (such as the use of well validated measures) should be relatively independent of grant funding. On balance, while Ost rightly highlights some methodological areas where ACT research could be improved, his technique of 'matching' ACT and CBT studies may be somewhat overly simplistic, as it fails to consider the wider context in which the research was carried out, and the reasons why a given methodology may have been selected.

Powers *et al.* (2009) carried out a meta-analysis of the ACT literature, including five additional studies to the review by Ost (2008). Powers found ACT to be superior to waiting list and psychological placebos (Hedge's  $g = 0.68$ ), to TAU ( $g = 0.42$ ), but not to be more effective than established treatments ( $g = 0.18$ ). The finding that ACT was not superior to established treatments was somewhat contrary to the findings of Hayes *et al.* (2006) and Ost (2008). The authors explain this difference in findings not only due to the inclusion of more studies, but also due to a few differences in opinion about whether certain treatment conditions are appropriately classified as psychological placebo, TAU, or established treatment. They also state, however, that changing the grouping of these debatable studies did not change their eventual result. Powers *et al.* (2009) did not view the lack of any superiority over established treatments as a relative weakness, as this is quite commonly the finding when comparing treatments, or psychotherapies (e.g. Powers *et al.*, 2008). The authors note, like Ost (2008), that the results of many ACT studies are difficult to interpret due to the comparison group being TAU. When there is no waiting list control or psychological placebo included, it is impossible to assess the efficacy of the TAU condition, and hence the comparison of ACT versus TAU becomes difficult to

interpret. Powers *et al.* (2009) recommend the inclusion of waiting list and /or psychological placebos as controls in future trials, and that ACT should be compared with ESTs in treating specific DSM-IV disorders. The authors appear to give an impartial and essentially positive review of the ACT literature.

Levin and Hayes (2009) carried out a reanalysis of Powers *et al.*'s (2009) data, having been provided access to their entire database. They describe in a brief 'letter to the editor' how they corrected minor numerical errors and missing data for 3 studies, and reclassified secondary or process variables as primary outcomes, and visa versa, as they saw appropriate for 11 studies. They also moved a study from TAU to active treatments, as they saw appropriate (viewing nicotine replacement patches and bupropion as an established treatment for smoking cessation, rather than TAU). Following these changes, they found ACT to be significantly superior to established treatments ( $g = 0.27$ ;  $p = 0.03$ ). Powers and Emmelkamp (2009) responded to Levin by stating that they stood by their decision to classify a nicotine 'patch' as TAU, as they did not view it as comparable with other more active established treatments included in the analysis such as CBT, CT, systematic desensitisation, or twelve-step facilitation. Thus, they defended their original conclusion. It is difficult to discern the 'winner' of this debate. The arguments were stated very briefly in letters to the editor, which are not subjected to peer review, and the judgements under debate are ultimately subjective. On balance however, it is perhaps somewhat ambitious of ACT to purport to be 'superior' to CBT, the most well evidenced psychological treatment in history, while simultaneously acknowledging itself to be at an early stage of development.

Finally, the most recent review of ACT literature was carried out by Ruiz (2010). Ruiz did not carry out a meta-analysis, but did conclude on the basis of those carried out (Hayes *et al.*, 2006; Ost, 2008; Powers *et al.*, 2009) that while ACT is established as being superior to control and TAU comparisons, further research is necessary to establish whether ACT is superior to established treatments, and that various methodological improvements should be made in comparison to many studies conducted thus far. Ruiz's review reads as being quite overtly 'pro ACT'. He notes



that the ACT research is impressively coherent, in that theoretical underpinnings of ACT are consistently supported by experimental and correlational studies, and are in turn mirrored by process analysis in outcome studies. Ruiz concludes that ‘In summary, ACT fundamental tenets seem to have a strong support in view of the correlational, the experimental psychopathology, and the outcome evidence.’ (p.148)

#### **1.4.6.2      *ACT as applied in chronic health conditions***

##### ***Chronic Pain***

Chronic pain is the health condition in which ACT has been most extensively researched to date. An ACT conceptualisation of chronic pain sees problems as arising for individuals when they engage in activities which produce short term relief from physical or psychological pain (such as remaining relatively inactive), but which prevent engagement in valued living in the longer term. With time, clients’ strategy of avoiding difficult psychological events produces a narrow and inflexible pattern of action, or psychological inflexibility (Wicksell, Renofalt *et al.*, 2008). ACT for chronic pain differs from other established treatments in that it does not primarily aim to reduce pain intensity, but rather aims to reduce the distressing and disabling influences of pain on valued living (McCracken *et al.*, 2005).

While CBT is established as an effective treatment for chronic pain (e.g. Morley *et al.*, 1999), McCracken *et al.* (2005) suggest that it has become something of a ‘compound phrase for a broad array of approaches’, so it is difficult to carry out a detailed analysis of treatment elements, or the direction of therapeutic action. The research reviewed in this section will demonstrate that ACT shows promising results in terms of treatment outcome, and has begun to elucidate behavioural processes that may be involved in successful treatment.

McCracken *et al.* (2005) reported the results of an ACT group intervention for chronic pain sufferers ( $N = 108$ ), carried out in a three or four week long residential

or hospital based setting. It is worth noting that the participants in this study had severe and long standing problems with pain, and had typically not significantly benefited from previous interventions. Post intervention, improvements were found in emotional, social, and physical functioning, along with reduced use of healthcare resources. At three-month follow-up a majority of improvements were maintained. Furthermore, improvements in most outcomes tended to correlate with increases in ‘acceptance’, as measured with the Chronic Pain Acceptance Questionnaire (CPAQ; McCracken *et al.*, 2004), suggesting that mechanisms of treatment proposed by ACT may have been active in treatment. This study had various limitations. Not least, there was no active comparison condition, so each patient’s wait prior to commencing treatment acted as their comparison.

A small RCT comparing an ACT intervention with medical treatment as usual (MTAU) was conducted by Dahl *et al.* (2004), for participants at a high risk of long-term disability and sick leave due to stress and pain symptoms. Participants in the ACT condition ( $n = 11$ ) received MTAU plus four one-hour weekly sessions of ACT, while those in the MTAU condition ( $N = 8$ ) simply received medical consultations as required. Post intervention and at six-month follow-up, the ACT condition showed significantly fewer sick days, and tended to use fewer medical treatment resources relative to the comparison condition, while not showing any significant differences in levels of pain, stress or QoL. This finding is perfectly consistent with the expectations of an ACT intervention, whereby the symptoms themselves need not be altered to facilitate behaviour change. Limitations to this research included: a small and relatively specific sample (consisting mainly of females), the lack of an active or placebo comparison condition, and the absence of any ACT process measures, or means to monitor therapist adherence to the specified treatment.

Results from experimental studies have also given support to the valuable role acceptance can play in living with pain. For example, Gutierrez *et al.* (2004) compared the ability of healthy participants to tolerate experimentally induced pain in a laboratory setting when given either: an acceptance based protocol (ACT), the

goal of which was to disconnect pain related thoughts and feelings from literal actions, or a control-based protocol (CONT) that focussed on changing or controlling pain-related thoughts and feelings' (p.1). While the control-based protocol produced greater reductions in a self-report measure of pain, participants in the ACT group tended to demonstrate greater pain tolerance and lower believability of the pain, so were willing to persevere with the task for longer. The results of this, and other such experimental studies, are impressively coherent with the theory underlying ACT, and with the results in terms of process variables during outcome studies.

While the evidence base for the effectiveness of ACT for chronic pain appears promising for its stage of development, along with evidence for the importance of acceptance as an important process variable, there is obviously a need for larger scale RCTs, with multiple comparison conditions (including traditional CBT as a treatment with proven efficacy). One recent RCT did directly compare the effects of group ACT and CBT interventions in a chronic pain population (Wetherell *et al.*, 2011). Participants in the ACT condition demonstrated improvements in regard to pain interference, symptoms of depression, and pain related anxiety. Outcome measures did not show any significant differences between the ACT and CBT conditions, though participants in the ACT condition reported significantly higher levels of satisfaction with their intervention.

It will be highly informative to continue research into the processes at work in both CBT and ACT. The need for such research is highlighted by the apparent contradiction in the literature at present, whereby evidence suggests strategies aimed at controlling pain can be unhelpful (e.g. McCracken *et al.*, 2007), while CBT for chronic pain, which apparently advocates such strategies, has proven efficacy (e.g. Morley *et al.*, 1999). One study design which could investigate this apparent paradox would be a RCT with the following three conditions: BA alone, BA plus CT, and full ACT. Such a design could elucidate the extent to which ACT and CBT are differentially effective in a chronic pain population, when the effects of BA are taken into account.

## *Diabetes*

A study by Gregg *et al.* (2007) compared a one-day diabetes management workshop, providing education alone, with a condition which had an additional ACT element aimed towards using acceptance and mindfulness skills to improve coping with difficult thoughts and feelings in relation to diabetes. Both conditions were delivered in a single three-hour session. At three-month follow-up participants in the ACT condition were more likely to employ ACT consistent coping strategies, and reported improved diabetes related self-care. ACT participants' glycated haemoglobin levels were also more likely to be in the target range. Mediation analysis showed that diabetes related acceptance (as measured with a version of the AAQ adapted specifically for this study) mediated the impact of treatment on glycemic control. The authors noted that an ACT approach may be well suited to this population, as engaging in self management behaviours (e.g. dietary control) may be likely to evoke distressing thoughts and feelings regarding their condition, which cannot be eliminated or suppressed. There were weaknesses to this study, including: the lack of any monitoring of adherence to treatment manuals, the delivery of the ACT intervention by a single clinician making therapist effects a possible confound, a relatively narrow range of self-management behaviours being assessed, and the use of a process measure with unknown psychometric properties.

## *Epilepsy*

Two RCTs (Lundgren *et al.*, 2006; Lundgren *et al.*, 2008) investigated the impact of ACT for drug refractory epilepsy. The first study (Lundgren *et al.*, 2006) compared the efficacy of nine group sessions of ACT and some behavioural seizure control technology, with a supportive therapy condition (designed to provide an equal amount of therapist attention while giving no active advice). Results showed that the ACT condition had significant effects on seizure frequency and duration, and QoL as compared to the comparison condition. One limitation of the study was that since the ACT condition also contained some seizure behaviour management techniques, it is

difficult to discern which elements of treatment were responsible for outcomes. It would have been preferable to have had seizure behaviour management techniques alone as an additional comparison condition, however, seizure frequency reduced before the delivery of the behavioural intervention, but after the beginning of the ACT intervention. A further RCT (Lundgren *et al.*, 2008) compared an ACT intervention (again with some additional seizure behaviour management techniques) with a yoga comparison. While both groups demonstrated increased QoL and reduced seizure frequency over time, ACT was found to reduce seizure frequency more than yoga. In this study, the ACT and yoga conditions had many treatment elements in common, including: mindfulness training, acceptance of private events, discussion of losses and taking action towards valued life directions, and the involvement of significant others in treatment. With both interventions being relatively broad in their scope, it is again difficult to know what the active elements of treatment were. The inclusion of process measures (such as the AAQ) would have been helpful to this end. The results of these studies do give preliminary support, however, for ACT being effective in reducing seizure frequency and increasing QoL of people with drug refractory epilepsy.

### *Smoking Cessation*

Gifford *et al.* (2004) investigated an ACT intervention for smoking cessation. The study compared an ACT intervention, which consisted of seven 50-minute individual sessions plus seven 90-minute group sessions (participants attending both sessions weekly for seven consecutive weeks), with Nicotine Replacement Therapy (NRT). While there were no differences between the groups post intervention, the ACT group showed better smoking outcomes at one year follow-up. While the differences between groups did not reach statistical significance in this relatively small sample ( $N = 76$ ), at follow-up the participants who had experienced the ACT intervention were more than twice as likely to have stopped smoking compared to the NRT participants. Improvements in the ACT group were found to be mediated by improvements in acceptance related skills. While the results give preliminary support for the utility of ACT in smoking cessation, and for the authors' hypothesis that

smoking may be maintained by experiential avoidance (as smoking can alleviate certain aversive internal states), it requires replication in a larger sample. The ACT intervention also appeared relatively labour intensive in terms of clinician time, with participants receiving quite extensive input in comparison with the NRT group. Future research could benefit from the inclusion of an attention placebo condition, and investigate whether participants could gain equivalent gains with fewer sessions.

### *Obesity*

Lillis *et al.* (2009) conducted a study investigating the effectiveness of ACT in improving the lives of obese individuals. The intervention did not target weight explicitly, but focussed on weight related stigmatising thoughts and distress, along with clarification of life values and fostering of behavioural commitments related to life values. The intervention was delivered in a one day six-hour workshop to 43 individuals with at least six months experience of weight loss programs. The ACT condition was compared with a waiting list control. At three-month follow-up the ACT participants showed larger reductions in weight related stigma (as indicated by a measure developed specifically for this study), body mass, and higher perceived QoL. There were, however, no measures in place to monitor treatment adherence in this study, and three-month follow up is a relatively short time period in the context of weight loss research (wherein benefits often do not endure in the longer term).

### *Multiple Sclerosis*

Only one published study to date has applied ACT with a MS population. Sheppard *et al.* (2010) investigated the effectiveness of a five hour ACT workshop focussed on teaching mindful acceptance, cognitive defusion, and value-guided action strategies to a group of individuals with MS ( $N = 15$ ). Self report measures were completed pre intervention, and again at three-month follow-up. Measures focussed on: MS related symptomatology and impairment, emotional functioning, fatigue, and ACT process domains. The ACT process measures comprised the White Bear Suppression

Inventory (Wegner *et al.*, 1987), a measure of individuals' tendency to suppress unwanted or aversive thoughts, and the Mindful Attention Awareness Scale (MAAS; Brown *et al.*, 2003). The results showed significant improvements in the domains of depression, extent of thought suppression, impact of pain on behaviour, and QoL. There were no significant changes in physical symptoms or mindfulness. The authors observed that the intervention was, of course, not designed or expected to improve physical symptoms of MS, but nonetheless appeared to impact positively upon mood and overall QoL. While it was expected that scores on the MAAS would improve, the authors suggest that perhaps three-month follow-up was too short a time period for this skill to be learned, as mindfulness does require quite extensive practice.

Sheppard *et al.* (2010) remarked that while more traditional CBT interventions in MS tend to have quite a specific focus (i.e. depression or fatigue), ACT has a very broad focus (targeting the functional underpinnings of multiple psychological problems), and thus may be suited to addressing the diverse challenges faced by PwMS. While this preliminary result suggests ACT merits further investigation in a MS population, there were various limitations to this study. Not least, this study had no control group, which would be an obvious inclusion in future research in larger samples. Also, the process measures were not completed mid-treatment, which is recommended when attempting to gather evidence for possible mediation. In the absence of a control group, some of the results may be attributable to demand characteristics of the research, although the authors suggest that the differential pattern of performance between different measures run counter to this possibility.

One published study (Grossman *et al.*, 2010) has investigated the effectiveness of Mindfulness training in a MS population. Grossman *et al.* (2010) compared a mindfulness intervention ( $N = 76$ ) with TAU ( $N = 74$ ) for PwMS. Those in the intervention group received eight weekly 2.5 hour group mindfulness classes, and one additional 7 hour session at week six. Participants were encouraged to carry out 40 minutes daily mindfulness practice as homework. Those in the treatment as usual group simply received one neurology appointment pre-intervention, one at six-month follow-up, with additional appointments as required. Primary outcomes included

disease-specific and non disease-specific health related QoL, depression, and fatigue. Employing an intention-to-treat analysis, the results showed that non-physical primary outcome measures improved significantly more in the mindfulness group compared to TAU, with effect sizes (Cohen's *d*) ranging from 0.4 to 0.9 post-treatment and 0.3 to 0.5 at six-month follow-up. The authors suggest that their results show the effectiveness of mindfulness interventions for improving health related QoL in a MS population. In the absence of an attention placebo or any other more active treatment control condition, however, it remains possible that the benefits demonstrated may be partly attributable to social contact and support, or placebo effects.

Grossman *et al.* (2010) also remarked how, in contrast to some CBT interventions for PwMS, mindfulness interventions have a potentially broad focus and impact, so may be particularly appropriate to be applied to the varied challenges faced by PwMS. This echoes the conclusions of Sheppard *et al.* (2010) regarding the potential appropriateness of ACT interventions for PwMS.

#### **1.4.7 The possible addition of ACT concepts to models of adjustment to Multiple Sclerosis**

Current models of adjustment to MS, such as that proposed by Dennison *et al.* (2009; see Figure 3), emphasise the importance of the beliefs that individuals form in relation to their health condition, the way they appraise their difficulties, and the coping strategies they employ. There has been an emphasis on the content of thought, which has guided to development of CBT interventions.

While 'acceptance' has been investigated in a MS population (Harrison *et al.*, 2004; Stuifbergen *et al.*, 2008), the definitions of 'acceptance' in these studies have been based on changes in the *content* of thought (see section 1.3.2.2.). Thus, mainstream (or 'non-ACT') adjustment literature has not yet taken into account the possible relevance of ACT processes such as acceptance (defined as a 'willingness' to



experience aversive states in the course of pursuing valued living) and cognitive defusion.

It is possible that ACT processes are significant mediators of adjustment which have not yet been investigated in this population. Dennison *et al.* (2009) suggest that ACT interventions may be particularly appropriate for PwMS since they do not involve challenging of thoughts about illness and symptoms; such thoughts may be accurate for PwMS, rendering CBT style verbal reattribution less appropriate. ACT techniques may be helpful in enabling PwMS to cope with unchangeable aspects of life that may be beyond personal control.

## **1.5 Current research**

In influential models of adjustment to chronic health conditions, such as the SCM (Lazarus & Folkman, 1984) and the CSM (Leventhal *et al.*, 1984), psychological processes, including appraisals of symptoms, are conceptualised as mediating the relationship between the experience of symptoms of illness and subsequent psychological adjustment. Consistent with these models, some appraisals of illness have been demonstrated to be significant variables in the process of psychological adjustment to MS (Dennison *et al.*, 2010). The modification of unhelpful illness appraisals can, therefore, be one of the focuses for CBT interventions, the most popular form of psychological intervention applied in a MS population (Dennison *et al.*, 2010).

ACT offers an alternative perspective on adjustment to chronic health conditions. ACT proponents (e.g. Hayes *et al.*, 2006) suggest that the way in which individuals *relate* to their internal experiences (such as their willingness to experience aversive states, and their level of ‘fusion’ with unwanted thoughts) in the course of pursuing valued living may be highly significant to the process of adjustment to chronic health conditions. Given this, it is possible that ACT processes (i.e. ‘acceptance’ and

‘cognitive fusion’) may also be important, with regard to the process of psychological adjustment to MS, in comparison to the content of illness appraisals. ACT processes have been found to be related to adjustment outcomes in individuals suffering from some chronic health conditions, and interventions targeting these processes show preliminary evidence for being effective (Ruiz, 2010). ACT interventions tend to focus on enabling individuals to relate differently to their experiences, as opposed to attempting to change their form or content, as can sometimes be the case in CBT.

The relevance of ACT processes has not, however, been extensively researched or investigated in a MS population. If ACT processes were found to be significant variables in the process of adjustment to MS, this would potentially offer support for an alternative perspective on the process of adjustment to MS in comparison to existing models. Specifically, it is possible that the manner in which PwMS *relate* to unwanted experiences (i.e. symptoms of MS, thoughts relating to their illness, and negative affect) while engaging in valued activity may account for variance in adjustment outcomes which is independent of the actual *content* of illness appraisals. Such a finding could provide support for the possibility of ACT interventions meriting further investigation in a MS population. This study was, therefore, considered to be a useful step in investigating whether ACT processes appear to be significant variables in the process of adjustment to MS, when compared in the same analytic model with relevant illness appraisals. This is the first study to directly address this question. This study was considered helpful in ascertaining whether ACT can offer any new or alternate perspective on adjustment to MS, which could inform the development of appropriate interventions in this population. Such development is necessary to broaden the range of interventions available to this population.

As psychological processes are conceptualised as mediating the relationship between the experience of symptoms of illness and subsequent psychological adjustment (Lazarus & Folkman, 1984; Leventhal *et al.*, 1984), it was considered appropriate to use multiple mediation analysis as a means to directly compare the extent to which

illness appraisals and ACT processes serve as mediating variables. The approach to multiple mediation analysis developed by Preacher and Hayes (2008) was chosen as a robust technique for determining whether different psychological variables significantly mediate the relationship between symptoms of MS and psychological outcomes, while also providing a direct comparison of the relative size of the effect mediated by each variable. This approach is suited to comparing competing mediation hypotheses (Preacher & Hayes, 2008). In the current research, this method of analysis was suited to compare hypotheses regarding the relationship between symptoms of MS and adjustment outcomes being mediated by either illness appraisals or by ACT processes. A cross sectional design, using standardised self-report measures (where possible) was chosen as a viable method of gathering data necessary for multiple mediation analysis. Questionnaires were selected to measure: MS symptom severity, illness appraisals, ACT processes, psychological distress, and satisfaction with life. This allowed the relationships between these variables to be explored as described above.

In summary, the rationale for the current study is as follows:

1. Previous research has suggested that appraisals significantly mediate the relationship between symptoms of illness and important outcomes such as distress and quality of life, both in people with chronic health problems in general and among PwMS specifically.
2. Previous research has also suggested that ACT processes significantly mediate the relationship between symptoms of illness and outcomes such as distress and quality of life in people with chronic health conditions such as pain, though this has not been tested among PwMS.
3. No study has yet compared the capacity of illness appraisals and ACT processes to mediate the relationship between physical symptoms and psychological outcomes in PwMS.
4. The multiple mediation technique outlined by Preacher & Hayes (2008) allows such multiple mediation modelling.

5. The results of the current research can suggest multiple pathways by which symptoms of illness may influence outcomes, which may provide novel targets and processes for psychological interventions.

### **1.5.1 Aim**

The current study aims to investigate the influence of two categories of psychological variable: cognitive appraisals and ACT processes (acceptance and cognitive fusion), on the relationship between symptoms of MS and subsequent psychological adjustment (i.e. psychological distress and satisfaction with life). Multiple mediation analysis (Preacher & Hayes, 2008) was chosen as the most appropriate statistical method for exploring the relationships between these variables. Such analyses can determine whether the psychological variables mediate the impact of MS symptomatology on adjustment, and compare the relative sizes of the effect mediated by each variable. This will be the first study to investigate the relationships between these variables in a MS population.

### **1.5.2 Hypotheses**

- 1) Cognitive appraisals will mediate the relationship between MS symptoms and symptoms of psychological distress.
- 2) ACT processes will mediate the relationship between MS symptoms and symptoms of psychological distress.
- 3) Cognitive appraisals will mediate the relationship between MS symptoms and satisfaction with life.
- 4) ACT processes will mediate the relationship between MS symptoms and satisfaction with life.
- 5) In comparison to cognitive appraisals, ACT processes will tend to be stronger mediators of the relationship between MS symptoms and outcome measures.

## **2 Methodology**

### **2.1 Design**

This study employed a quantitative methodology, as this was considered most appropriate for the aims of the research. A cross-sectional design was used, with participants each completing a single pack of questionnaires.

### **2.2 Participants**

Participants were clients with a diagnosis of MS known to the NHS services participating in the research:

- Fife Rehabilitation Service (FRS), NHS Fife.
- Community Rehabilitation and Brain Injury Service (CRABIS), Livingston, NHS Lothian.
- Scottish Brain Injury and Rehabilitation Service (SBIRS), Astley Ainslie Hospital, Edinburgh, NHS Lothian
- MS service, Department of Clinical Neurosciences, Western General Hospital, Edinburgh, NHS Lothian.

#### **2.2.1 Inclusion Criteria**

The principle inclusion criterion was for participants to be clients (minimum age 18) of participating services and to have a Neurologist confirmed diagnosis of MS.

### **2.2.2 Exclusion Criteria**

- Individuals who had other co-morbid health problems which could introduce heterogeneity to the sample, either physical (e.g. additional acquired brain injury, arthritis, chronic obstructive pulmonary disease etc.) or psychiatric (e.g. psychotic disorders) in nature.
- Individuals with impairment in intellectual functioning which could negatively impact upon their ability to give informed consent, or understand and complete the questionnaires.
- Individuals with a grasp of the English language that could make it difficult for them to give informed consent, or understand and complete the questionnaires.

## **2.3 Measures**

Self-report measures were decided to be most appropriate for the current study. Measures were carefully selected to measure theoretically relevant constructs while minimising response burden, and difficulty of completion, for PwMS who may have some deficits in cognitive functioning.

### **2.3.1 Multiple Sclerosis Impact Scale (MSIS-29)**

Hobart *et al.* (2001, 2004)

The MSIS-29 (see appendix 6.1) was developed as a self-report measure of MS symptoms. It has 2 subscales, measuring the physical (20 items) and psychological (9 items) symptoms of the disease. Statements pertaining to individuals' subjective experience of symptoms of MS are rated on a 5-point Likert scale (1 = "not at all", 5 = "extremely"). Though respondents completed the whole MSIS-29, only the 'physical' subscale (MSIS-physical) was used in analysis. The 'psychological'

subscale (MSIS-psychological) showed strong theoretical overlap with outcome measures so could have confounded results.

The authors of the MSIS-29 (Hobart *et al.*, 2001) note that the lack of well validated measures of MS symptomatology has led to more generic measures such as the 36-item Short-Form Health Survey (SF-36; Ware *et al.*, 1993) often being employed with PwMS. Psychometric limitations of the SF-36 in a MS population include significant floor and ceiling effects, and limited responsiveness (Freeman *et al.*, 2000). Generic measures can also sometimes neglect areas of impact which are disease specific. The MSIS-29 was developed by initially generating a large number of items (129) from interviews with PwMS, before item reduction analysis was carried out.

The MSIS-physical shows good variability, low floor and ceiling effects, and good internal consistency ( $\alpha \geq 0.91$ ) and test-retest reliability ( $r \geq 0.87$ ). Correlations with other measures, including the SF-36 and the General Health Questionnaire (GHQ-12; Goldberg & Hillier, 1979) support the validity of the MSIS-29. Effect sizes ( $g = 0.82$ ) for the MSIS-physical demonstrate good responsiveness to changes in symptoms (Hobart *et al.*, 2001). Hobart *et al.* (2005) provide evidence for the MSIS-physical being the most responsive self-report measure in detecting changes in physical symptomatology when compared with the GHQ-12, SF-36 and the Functional Assessment of MS (FAMS; Cella *et al.*, 1996). Furthermore, support for the reliability, validity and responsiveness of the MSIS-29 was demonstrated by Costelloe *et al.* (2007) by having PwMS complete the MSIS-29 and the Expanded Disability Status Scale (EDSS; Kurtzke, 1983) at baseline and four-year follow-up. The EDSS is the measure of MS related disability most widely used by neurologists, so served as the 'anchor measure' with which to compare the MSIS-physical. The MSIS-physical was found to perform well over time, and the authors concluded it is suitable as an outcome measure among PwMS.



### 2.3.2 Illness Cognition Questionnaire (ICQ)

Evers *et al.* (2001)

The ICQ (see appendix 6.2) was designed to assess illness related cognitions across different chronic diseases. The ICQ is based on literature outlined earlier (e.g. Lazarus & Folkman, 1984; Leventhal *et al.*, 1984) which recognises illness cognitions as mediating the relationship between stress and illness. The ICQ consists of 3 subscales, based on 3 possible types of evaluations that can be made of a long-term stressor: ‘helplessness’ (hereon referred to as ICQ-helplessness), attributing aversive meaning to the disease; ‘acceptance’, diminishing the aversive meaning; and ‘perceived benefits’ (hereon referred to as ICQ-perceived-benefits), adding a positive meaning to the disease (e.g. “I have learned a great deal from my illness”). Respondents rate the extent to which they agree with each item on a four point Likert scale (1 = not at all, 4 = completely).

The ‘acceptance’ subscale was not utilised in the current study. An ACT consistent conceptualisation of acceptance was considered to be better captured by other measures, so the ICQ ‘acceptance’ subscale was excluded in the interest of minimising item burden for respondents. It would, however, have been preferable to include the acceptance subscale to provide a measure of an alternative conceptualisation of ‘acceptance’. As discussed further in section 4.3.1, including only one conceptualisation of acceptance does introduce some inherent bias to the interpretation of results. Inclusion of the ICQ ‘acceptance’ subscale would have afforded more scope for the significance of an ACT conceptualisation to be disconfirmed, and for an alternate perspective on acceptance to be explored. Excluding the acceptance subscale obviously changed the order in which items were completed by respondents. This change in response-order could have subtle impacts upon the manner in which items are responded to (Krosnick & Alwin, 1987) in comparison to how they were answered among the normative sample, but such differences would hopefully be relatively minor. Fortunately, Evers *et al.* (2001)

provided separate normative data for each subscale of the ICQ, which facilitates their potential use independently of each other.

The ICQ was originally developed with a sample of patients suffering from rheumatoid arthritis ( $N = 263$ ) and MS ( $N = 167$ ). The ICQ demonstrated good reliability in the MS sample, with  $\alpha$  values of .88 for ICQ-helplessness, and .85 for ICQ-perceived-benefits. These subscales also showed evidence of concurrent and predictive validity in relation to measures of physical health, psychological health, and coping. As expected, helplessness cognitions appear to have a maladaptive function, while perceived benefits appear to have an adaptive function in the physical and psychological health outcomes of PwMS.

### **2.3.3. The Brief Illness Perceptions Questionnaire (brief-IPQ)**

Broadbent *et al.* (2006)

The brief-IPQ (see appendix 6.3) was developed as a short version of the IPQ-R (Moss-Morris *et al.*, 2002) to rapidly assess the cognitive and emotional representations of illness. Like the IPQ-R, it is theoretically based on Leventhal *et al.*'s (1984) model of illness representations (see chapter 1.3.2.). The brief-IPQ requires participants to use an 11-point Likert scale (with value labels varying between items) to rate how they experience their illness in regards to the various dimensions, each represented with a single item.

Illness representations in MS have previously been investigated with the IPQ-R (Jopson & Moss-Morris, 2003), and the brief-IPQ (Dennison *et al.*, 2010). The brief-IPQ was used in preference to the IPQ-R in this study to minimise item burden for participants. Moderate to good associations exist between equivalent dimensions of the brief-IPQ and the IPQ-R. The brief-IPQ has shown good predictive validity among a sample of patients recovering from myocardial infarction (MI), with scores on the 'consequences', 'identity', 'concern', 'understanding' and 'emotional

response' subscales at discharge relating to mental and physical functioning at three-month follow-up (Broadbent *et al.*, 2006)

While respondents completed the whole brief-IPQ, not all subscales of the brief-IPQ were included in analysis. Only the following three subscales were included:

**IPQ-personal-control** : “How much control do you feel you have over your illness?”

**IPQ-concern** : “How concerned are you about your illness?”

**IPQ-understanding** : “How well do you feel you understand your illness?”

‘Personal control’ and ‘understanding’ have been highlighted in previous research using the IPQ (Vaughan *et al.*, 2003) and IPQ-R (Jopson & Moss-Morris, 2003) as being significant constructs in predicting adjustment outcomes among PwMS. The ‘concern’ subscale is new to the brief-IPQ (so was not included in previous research investigating illness representations in MS), but appears to have good face validity in capturing appraisals of MS symptoms as threatening and stressful. Such cognitions have been highlighted by Dennison *et al.* (2009) as being associated with adjustment difficulties.

The other subscales of the brief-IPQ were variously disregarded from analysis for appearing overly confounded with symptom or outcome measures, or for having low face validity in terms of their relevance for PwMS. The ‘consequences’ (the degree to which individuals perceive their illness as affecting their life) and ‘identity’ (the degree to which individuals believe they experiences symptoms of their illness) subscales were considered to be overly confounded with the MSIS, the measure of MS symptomatology. The ‘emotional’ subscale (the degree to which individuals believe their illness affects them emotionally) was considered to be overly confounded with the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The ‘timeline’ subscale (the length of time individuals believe their illness will continue) may have relatively limited relevance for a MS population when represented as a single item. MS inherently continues indefinitely. The timeline

subscale of illness representations would perhaps have more relevance for a MS population when measured with multiple items by the IPQ-R, which can capture beliefs of the disease being cyclical in nature. Finally, the ‘treatment control’ subscale (the extent to which individuals believe their treatment can ‘help’ their disease) has not been found to be strongly related to outcome measures in previous illness representation research (e.g. Jopson & Moss-Morris, 2003; Vaughan *et al.*, 2003). The influence of beliefs regarding ‘treatment control’ may also be partly captured by the ‘personal control’ subscale. The brief IPQ ‘personal control’ subscale actually correlates slightly more strongly with the ‘treatment control’ subscale of the IPQ-R ( $r = .34$ ), compared to the correlation of the brief IPQ ‘treatment control’ subscale with its IPQ-R counterpart ( $r = .32$ ).

Of course, illness representation research does typically include analysis of all subscales of the measure employed, so all elements of Leventhal *et al.*’s (1984) original model can be investigated. In the context of the current research aims, however, it was considered appropriate to select a small number of illness representations that have been demonstrated to be particularly relevant by previous research, and which avoid problems of confounding with other measures employed. When considered alongside the ICQ-helplessness and ICQ-perceived-benefits, the IPQ-personal-control, IPQ-concern, and IPQ-understanding subscales were considered to contribute appropriately to a wide and highly relevant selection of illness related appraisals.

#### **2.3.4. The Acceptance and Action Questionnaire- II (AAQ-II)**

Bond *et al.* (in press)

The AAQ-II (Bond *et al.*, in press) is a revised version of the original Acceptance and Action Questionnaire (AAQ; Hayes, Strosahl, Wilson *et al.*, 2004), developed to overcome psychometric shortcomings of the original version. The AAQ had been demonstrated to yield low alpha values for internal consistency, a problem thought to be due to unnecessary item complexity, along with the subtlety of concepts addressed.

The AAQ-II is a unidimensional measure which assesses the construct of psychological inflexibility. Psychological inflexibility involves an individual being unwilling to experience aversive internal states in the interest of pursuing valued goals, so their behaviour becomes more focussed on altering the form and/or frequency of these internal events (Hayes *et al.*, 1999). Respondents rate items in terms of their truth on a seven-point Likert scale (1 = never true, 7 = always true).

While the AAQ-II was initially intended as a ten-item scale, the authors found that a seven-item version demonstrated the most satisfactory psychometric properties. From a diverse sample of 2,816 individuals, the AAQ-II demonstrated satisfactory structure, reliability and validity. Results demonstrated a mean  $\alpha$  coefficient of .84 (range .78-.88), and 3-month (.81) and 12-month (.79) test-retest reliability. The AAQ-II also shows expected relationships with constructs to which it is theoretically tied, including symptoms of depression, anxiety, and stress.

Participants' scores on the AAQ-II were not included in mediational analysis, but were used to calculate a Spearman correlation coefficient with the Multiple Sclerosis Acceptance Questionnaire (MSAQ; described in section 2.3.6.).<sup>1</sup> The AAQ-II was not included in mediational analysis, primarily because an illness specific measure of acceptance was thought to be more appropriate for the current study. The AAQ-II can be seen in appendix 6.4.

### **2.3.5 The Cognitive Fusion Questionnaire (CFQ)**

Gillanders *et al.* (2010)

The CFQ (see appendix 6.5) is a 13-item self-report measure of cognitive fusion. Respondents rate items in terms of their truth on a seven-point Likert scale (1 = never

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<sup>1</sup> The AAQ-II showed a strong correlations ( $r_s = -.59$ ,  $n = 125$ ,  $p < .001$ ) with the MSAQ, and the Cognitive Fusion Questionnaire (CFQ;  $r_s = .74$ ,  $n = 129$ ,  $p < .001$ ). Relatively strong covariance, evidenced by the high correlations, with the MSAQ and the CFQ was also contra-indicative of its inclusion in mediational analyses (Preacher & Hayes, 2008).

true, 7 = always true). The CFQ is based on a broad definition of fusion, focussing not only on the believability of thoughts, but also including items targeting: literality, entanglement, struggle, engagement and entanglement with thoughts, and taking action as opposed to thinking.

Across four separate community based samples (total  $N = 1072$ ) the CFQ has demonstrated good reliability ( $\alpha = .86$ ), and has also shown good one-month test-retest reliability ( $r = .82, p < .001, N = 74$ ). The CFQ has a theoretically coherent single factor structure, and correlates in expected directions with related constructs, including: experiential avoidance, distress, symptoms of depression, mindfulness, and satisfaction with life. Additionally, the CFQ has shown preliminary evidence of good reliability among clinical samples ( $N = 169, \alpha = .87$ ), and can distinguish individuals suffering high levels of psychological distress from healthy controls.

High correlations (approximately  $r = .8$ ) have been found between the CFQ and the AAQ-II, supporting the notion that psychological inflexibility (as measured by the AAQ-II) and cognitive fusion are highly related constructs. Gillanders *et al.* (2010) note that while the AAQ-II measures psychological inflexibility across different domains (i.e. cognition, emotion, memories and behaviours), the CFQ focuses more exclusively on the cognitive domain.

### **2.3.6 The Multiple Sclerosis Acceptance Questionnaire (MSAQ)**

The MSAQ is a measure adapted from the CPAQ (McCracken *et al.*, 2004) especially for this study.

#### **2.3.6.1 Rational for the adaptation of a MS specific measure**

The measures of appraisals (the ICQ and brief-IPQ subscales) relate directly to the experience of illness. In carrying out a comparison of the importance of cognitive appraisals to ACT processes, it would be a loaded comparison if the measures of

appraisals were specific to illness, while all measures of ACT processes were more generic. McCracken and Zhao-O'Brien (2010) have demonstrated that general acceptance (as measured with the AAQ-II) and illness-specific acceptance are overlapping but independent constructs, at least in relation to chronic pain. For these reasons, the adaptation of a MS specific measure of acceptance was deemed necessary to effectively test the hypotheses of the current research.

#### **2.3.6.2      *Rationale for use of the CPAQ as a template for adapted measure***

The CPAQ was originally developed by Geiser (1992; as cited by McCracken *et al.*, 2004), but has subsequently been refined by McCracken (1999) and colleagues (McCracken *et al.*, 2004). McCracken *et al.*'s (2004) refinements produced a 20-item measure, consisting of two subscales: activity engagement, and pain willingness. Activities engagement involves the pursuit of valued life activities while pain is being experienced, and pain willingness relates to recognition that attempts to avoid or control pain are often ineffective. The measure has good internal consistency, demonstrating  $\alpha$  values of .82 for the activity engagement subscale, and .78 for pain willingness. McCracken *et al.* (2004) found individuals who scored higher on the CPAQ tended to report: superior physical and work related functioning, lower levels of emotional distress, less use of medication and health services, and less pain. As previously described, the CPAQ has been used (e.g. McCracken *et al.*, 2005; Vowles *et al.*, 2009) as a measure of treatment process in ACT interventions for chronic pain, and has demonstrated that changes in pain related acceptance appear to be active elements in effective treatment.

Given its sound psychometric properties, the CPAQ was chosen as an appropriate condition specific measure on which to base a MS specific measure. While chronic pain and MS are by no means identical conditions, the two dimensional factor structure of the CPAQ (activities engagement and willingness) provides a theoretically sound working definition of acceptance for application in a MS population. The process of adjusting to MS in an effective manner does inherently

involve continuing to engage in personally valued activity as much as possible. In the course of engagement in such activity, symptoms and limitations of the condition are likely to be experienced, along with potentially upsetting cognitions relating to these experiences. Some *willingness* to have such experiences without attempts to avoid or control them may be adaptive. Of course, MS is sometimes inherently limiting, giving individuals no choice regarding whether to engage in activity or not, but this does not preclude the possibility of acceptance being a relevant and adaptive process in many situations. It is, of course, equally possible for chronic pain (and symptoms of other chronic health conditions) to reach such levels that further activity is impractical or unwise.

### **2.3.6.3      *Scale Adaptation***

The items for the MSAQ were initially adapted from the CPAQ through consultation between the principal investigator, his supervisor (who is an experienced ACT clinician) and various Clinical Psychologists and Clinical Neuro-psychologists based in participating NHS services, with extensive experience of working with PwMS.

While many items were appropriately adapted by substituting the word ‘pain’ for ‘symptoms of MS’, others needed more careful modification to be appropriate and sensitive to the disease specific limitations of MS. For example, item 15 of the CPAQ, “When my pain increases, I can still take care of my responsibilities”, was adapted to “When my symptoms of MS increase or relapse, I can still try my best to do the things I most care about”, as for some individuals it would be unfair to imply that it may be possible to take care of one’s responsibilities despite severe symptoms.

While the CPAQ uses a seven-point Likert scale for participants to rate the items on, with values ranging from zero to six, the MSAQ uses an identically labelled seven-point scale, but with the numeric label ranging from one to seven (1 = “never true”, 7 = “always true”). This change was to make the Likert scale consistent with those of the CFQ, AAQ-II and Satisfaction with Life Scale (SWLS), to save participants the cognitive burden of switching to another slightly different scale.



#### **2.3.6.4 Pilot Work and Scale Refinement**

The first version of the MSAQ was issued to 4 pilot participants (see section 2.4.1). The participants reported finding the items of the questionnaire to be appropriate, acceptable, and easily comprehensible. The only criticism of item wording was of the initial wording of item seven (“I need to concentrate on getting rid of my symptoms of MS”), because it is not necessarily possible to ‘get rid’ of MS symptoms. This item was changed accordingly (“I need to concentrate on doing all I can to reduce the symptoms of MS”). A more user friendly answering format (the same as the MSIS-29, which was developed specifically for PwMS) was also adopted to be visually clearer and less cognitively taxing.

The final items of the MSAQ can be seen in a table in appendix 6.6, where they can readily be compared with the original CPAQ items. The appendix also contains the scoring instructions for the questionnaire. A final version of the MSAQ, as issued to participants, can be seen in appendix 6.7.

#### **2.3.6.5 Correlation between the MSAQ and AAQ-II**

As previously stated, a Spearman correlation coefficient was calculated between the AAQ-II and MSAQ, showing a strong correlation ( $r_s = -.59$ ,  $N = 125$ ,  $p < .001$ ). This provides some preliminary evidence for the validity of the MSAQ as a measure of ‘acceptance’ as conceptualised in an ACT model.

#### **2.3.7 The Hospital Anxiety and Depression Scale (HADS)**

Zigmond & Snaith (1983)

The HADS (appendix 6.8) was originally developed (Zigmond & Snaith, 1983) for use in a general medical outpatient setting, but has since become very widely used in

both clinical and research settings (Herrmann, 1997). It is a brief, 14-item, measure with two subscales, measuring symptoms of anxiety and depression. The two subscales can be summed to give a total score of psychological distress.

The HADS has good psychometric properties. In a large ( $N = 1792$ ) UK sample (Crawford *et al.*, 2001), the anxiety and depression subscales were found to have  $\alpha$  values of .82 and .77 respectively, with the total score yielding a value of .86. The correlation between the subscales was found to be moderate in magnitude ( $r = .53$ ).

Being a brief measure, the HADS has a low item burden, and is easy to complete. Hence, it was considered suitable for use in this study. It has been used previous research with PwMS, including research investigating the relationship between illness representations and adjustment (e.g. Spain *et al.*, 2007; Vaughn *et al.*, 2003). Furthermore, one study found that cognitive impairment in MS does not affect the reliability and validity of the HADS (Gold *et al.*, 2003).

The interpretation of the HADS is generally based on cut-off scores. Though there is no absolute single set of cut-off scores which are used (Herrmann, 1997), the scores recommended by the original authors for each of the subtests are: mild = 8-10, moderate = 11-15, and severe = 16 or above (Snaith & Zigmond, 1994). A recent study (Honarmand & Feinstein, 2009) validating the HADS for use with PwMS recommended a threshold score of eight on either of the subscales as offering optimal sensitivity and specificity for detecting potentially clinically significant levels of symptoms of anxiety or depression. Hence, a score of eight was used as the threshold score beyond which symptoms of anxiety or depression of respondents were reported to their GP.

### **2.3.8. The Satisfaction With Life Scale (SWLS)**

Diener *et al.* (1985)

The SWLS (appendix 6.9) is measure of global life satisfaction. It is a very brief measure, consisting of only 5 items, and has a single factor solution. The authors of

the scale (Diener *et al.*, 1985) demonstrated it to have good internal consistency ( $\alpha = .87$ ) and moderate test-retest reliability ( $r = .82$ ). Respondents rate the extent to which they agree with the five items (e.g. “I am satisfied with my life.”) on a seven-point Likert scale (1 = strongly disagree, 7 = strongly agree).

The SWLS was developed from a positive psychology tradition. For the current study, it was thought prudent to include an outcome measure associated with well-being in addition to the HADS, which focuses on symptoms of negative affect. The inclusion of a more positively oriented outcome measure is perhaps particularly appropriate given that ACT constructs are under investigation. From an ACT perspective, the importance of acceptance and cognitive defusion are only important insofar as they enable individuals to engage in valued living, a concept which is surely theoretically linked to life satisfaction. The SWLS has previously been used as an outcome measure in ACT research (e.g. Johnston *et al.*, 2010; Lundgren *et al.*, 2008), and in studies investigating the process of psychological adjustment to MS (e.g. Pakenham, 2005).

Other more inclusive measures of QoL were considered for use as measures of adjustment, such as the World Health Organisation Quality of Life Assessment brief version (WHOQOL-BREF; The WHOQOL Group, 1998). Broader measures such as the WHOQOL-BREF, which enquire after more external variables such as housing conditions, may have introduced variance that would not be expected to be related to the cognitive processes under investigation. For the current study, it was thought to be more theoretically coherent to focus exclusively on measures of psychopathology (the HADS) and life satisfaction (the SWLS). Also, some items on the WHOQOL-BREF appeared somewhat similar to items on the MSIS-29, which could have confounded results.

### **2.3.9 Demographics**

Participants were asked to provide some basic demographic data: age, gender, years since diagnosis, relational status, and type of disease (relapse/remitting or

progressive in nature). This data was collected so these variables could be explored as possible covariates, and controlled for in analysis if necessary. The form used to gather this information can be seen in appendix 6.10.

## **2.4 Procedures**

### **2.4.1 Conduct of pilot work**

Initial pilot work was carried out with four participants with diagnoses of MS known to Fife Rehabilitation Service. These participants were willing to read the information sheet, complete the consent form, complete the questionnaire pack, and provide some feedback to the principal investigator afterwards. Participants all found the information sheet and consent form clear and understandable. Reported times to complete the questionnaire pack varied between 15 and 45 minutes. One of the pilot participants suggested the answering format of some of the questionnaires could potentially be altered to be visually clearer, and less cognitively taxing. In line with their suggestions, the answering format of all questionnaires (except the HADS, which was used in its official licensed form) were adapted, so they were the same as the MSIS-29, which has a particularly user friendly response format developed specifically for PwMS.

### **2.4.2 Identification of suitable participants**

Suitable participants (in relation to inclusion/exclusion criteria) were identified by any member of the direct care team (i.e. Doctors, Clinical Psychologists, MS Nurses, Physiotherapists, Occupational Therapists, Dieticians) working in participating NHS services. This occurred in two ways:

- 1) At the request of the principal investigator, clinicians were vigilant for suitable participants among those attending services for an appointment in the course of their routine care.
- 2) Clinicians identified suitable participants among a database of patients, so research packs could be sent out to them by post.

Clinicians identifying potential participants were aware of inclusion and exclusion criteria of the study, including the need for individuals to be of a sufficient cognitive ability to give informed consent and complete questionnaires in a meaningful way. The option of performing a brief cognitive screening of potential participants was considered to gain a more objective measure of their cognitive functioning, but such a labour intensive procedure was simply not feasible for the current research. The cognitive capacity of potential participants was made through clinical judgement by a member of staff who was familiar with them. Previous research (Gold *et al.*, 2003) has found that even among PwMS with measured cognitive impairment the reliability and validity of self-report health measures (including the HADS) is not affected, so relatively mild cognitive impairment among some respondents in the current research would be unlikely to adversely affect results obtained.

### **2.4.3 Approach of potential participants**

Participants were approached by a member of their direct care team during a routine appointment and asked whether they would be interested in participating in this research. They were given a brief verbal explanation of the study, and if they were interested in learning more, they were issued with a research pack containing the participant information sheet (appendix 6.11), the consent form (see appendix 6.12), the questionnaires, and a pre-paid envelope to return their responses if they chose to participate.

Individuals were instructed to take the packs home with them so they could read them in their own time and consider whether they wished to participate. If they chose to participate, they could post completed questionnaires back in the pre-paid envelope.

At two of the research sites (FRS and CRABIS) potential participants were also approached by having a research pack sent to them through the mail. The pack contained the participant information sheet, the consent form, the questionnaires, and a pre-paid envelope to return their responses if they chose to participate. The information sheet named the member of the direct care team (familiar to them) who had identified them as a potentially suitable participant for this research. The information sheet was clearly addressed as having come from the service which they attended, and was signed by a senior clinician in that service and the Principal Investigator.

#### **2.4.4 Data collection, data storage, and participant confidentiality**

Data was collected by participants simply sending the completed consent form and questionnaires back to the Principal Investigator in a pre-paid envelope.

The consent forms contained participant identifiable information, while the completed questionnaires did not. Therefore, consent forms and completed questionnaires for each participant were marked with a unique code identifier, and stored in separate locked filing cabinets at the Principal Investigator's base, so the data obtained from questionnaires remained anonymous. This anonymised data was entered into a password protected computer for statistical analysis.

#### **2.4.5. Response to the report of high levels of symptoms of anxiety or depression.**

Participants were made aware on the consent form that their General Practitioner (GP) would be informed of their participation if they chose to participate (appendix 6.13). Additionally, it was explained that if their scores on either the anxiety or depression subscales of the HADS suggested potentially clinically significant levels of anxiety or depression, then their GP would also be informed of this (appendix 6.14). In this eventuality their details would, of course, need to be retrieved from their consent form by use of the unique code identifier. Honarmand and Feinstein (2009) recommend a score of eight on either the anxiety or depression subscale of the HADS as having optimal sensitivity and specificity for potentially clinically significant levels of anxiety or depression. Therefore, if a participant's score on either subscale exceeded eight, their scores for both subscales were included on the letter to their GP, so their GP could take whatever further action they deemed appropriate. 30.2 per cent of participants scored eight or above on the anxiety subscale, and 25.6 per cent scored eight or above on the depression subscale, so had their scores included on the letter to their GP.

### **2.5 Statistical Analysis**

All statistical analysis was carried out with Predictive Analytics Software (PASW) version 17.

#### **2.5.1 Power analysis**

Previous research (e.g. Broadbent *et al.*, 2006; Evers *et al.*, 2001; Vaughan *et al.*, 2003; Vowles *et al.*, 2007) has found moderate relationships between illness appraisals and outcome measures. Thus, it seemed reasonable to hypothesise moderate relationships between the variables in the current study. Power calculations

were conducted accordingly, for the ability to detect moderate effect sizes (i.e. Cohen's  $d$  of 0.5 to 0.8).

For the ability to detect moderate effect sizes, Green (1991) recommends the use of the formula  $N \geq 50 + 8m$  for testing the overall fit of a regression model (where  $N$  is the number of participants, and  $m$  the number of predictor variables), and the formula  $N \geq 104 + m$  for testing individual predictor variables within the model. The multiple mediation approach (Preacher & Hayes, 2008) used in this study employs regression coefficients for bootstrapping, so the formulas proposed by Green (1991) were deemed appropriate for conducting approximate power calculations.

The eight predictor variables used for this study (MSIS-physical, two subscales of the ICQ, three subscales of the brief-IPQ, the MSAQ, and the CFQ), therefore suggested the use of approximately 114 participants based on the formula  $N = 50 + 72$  (yielding the greater number of participants of the two formulae).

### **2.5.2. Preliminary analyses**

Preliminary exploration of the data was conducted with the use of descriptive statistics, Pearson correlations, and independent sample t-tests. Transformations were carried out on data from certain measures to ensure that data used in preliminary analyses met parametric assumptions.

### **2.5.3. Testing of research hypotheses**

The main hypotheses of this study were tested with multiple mediational analyses, as described by Preacher and Hayes (2008). The essential principles underlying this approach, and the interpretation of statistical output produced, are hereby discussed.



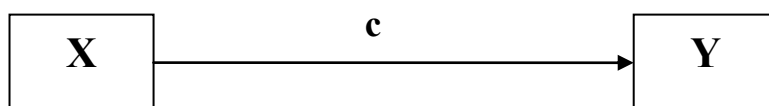
### 2.5.3.1. Underlying theory in testing models of mediation

Panel A of Figure 6 illustrates a situation where variable X (the independent variable) has an effect on Y (the dependent, or outcome, variable), with no variables mediating the relationship. Panel B introduces a possible multiple mediation model where variables  $M_1$  and  $M_2$  mediate the relationship between X and Y. The abbreviations in Figure 6 and the ensuing discussion are defined as follows:

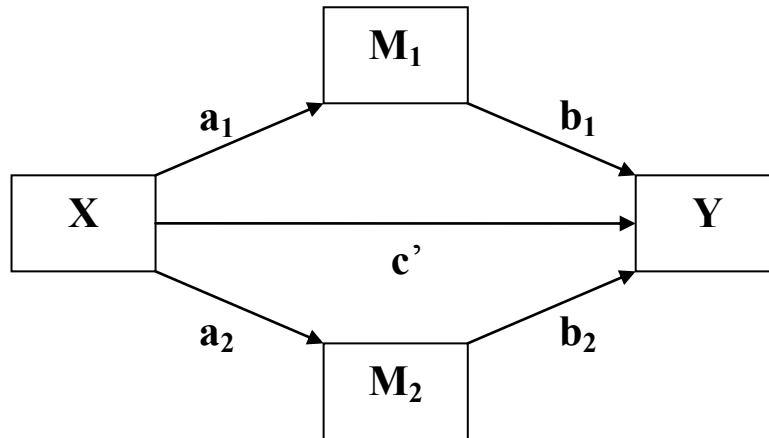
- a** – the effect of X on the proposed mediator
- b** – the effect of the proposed mediator on Y, controlling for a
- ab**– the product of a and b, the *specific indirect effect* of X on Y through a given mediator ( $a_1b_1$  **or**  $a_2b_2$  in Panel B)
- c** – the *total effect* of X on Y, not controlling for other paths
- c'**– the *direct effect* of X on Y, controlling for the indirect effects of the ab routes (i.e.  $c' = c - a_1b_1 - a_2b_2$ )

The *total indirect effect* through the mediators can be calculated by summing the specific indirect effects ( $a_1b_1 + a_2b_2$ ), or by subtracting the *direct effect* from the *total effect* ( $c - c'$ ).

#### Panel A



Panel B



**Figure 6: Illustration of a multi-mediation design**  
(Adapted from Preacher & Hayes, 2004)

The *causal steps* approach, proposed by Baron and Kenny (1986), has been the most popular in testing hypotheses of mediation (Hayes, 2009). Within this approach, multiple regression analyses or structural equation modelling would typically be used to test the following hypotheses: X significantly predicts Y (path c), X significantly predicts M (a paths), M significantly predicts Y controlling for X (b paths), and the effect of X on Y decreases substantially when the effects of the mediators are controlled for (i.e.  $c'$  is substantially smaller than c). If these criteria are met, this would be interpreted as evidence of given variables acting as mediators (Preacher & Hayes, 2008). While still commonly used by researchers, the Baron and Kenny (1986) approach has been subject to criticism. It has been found to be low in power to detect significant effects (MacKinnon *et al.*, 2002), and the actual intervening effect is not directly tested, but rather logically inferred from the testing of the four hypotheses listed above (Hayes, 2009). Sobel (1982) developed a technique to directly test the statistical significance of indirect effects, sometimes referred to as a 'product of coefficients approach', but this method has been criticised for assuming that the sampling distribution of the indirect effect meets parametric assumptions, when this is often not the case (Hayes, 2009; Shrout & Bolger, 2002).

### **2.5.3.2.      *The ‘bootstrapping’ method of multiple mediation analysis used in the current study***

Preacher and Hayes (2004; 2008) describe a method for directly testing the statistical significance of indirect effects in a multiple mediation model non-parametrically, so the normal sampling distributions of indirect effects are not assumed. Including multiple mediators in the same model (as opposed to running numerous simple models, testing single mediators) makes it possible to determine to what extent a given variable acts as a mediator while controlling for the effects of other variables entered in the model, reduces the risk of Type 1 errors due to the omission of significant variables, and enables a comparison of the different sizes of the indirect effects associated with each proposed mediating variable (Preacher & Hayes, 2008).

To provide a nonparametric analysis, Preacher and Hayes recommend ‘bootstrapping’. Bootstrapping involves repeatedly taking small samples with replacement (i.e. the same case can be sampled repeatedly) from the original sample. Each of these smaller samples (called ‘bootstrap samples’) provides an estimate of the total and specific indirect effects (measured as regression coefficients) of X on Y in the original sample. The sample is effectively being treated as a population from which the smaller bootstrap samples can be taken (Field, 2009). Preacher and Hayes (2008) recommend taking at least 5000 bootstrap samples from the original data set. The values obtained from the bootstrap samples are then sorted from high to low, producing an ‘empirical approximation of the sampling distribution’ of given effects. A confidence interval (CI), typically of 95 per cent, can then readily be applied to these estimated effects, providing a ‘percentile bootstrap CI’ (Preacher & Hayes, 2008). These 95 per cent CIs are then ‘bias corrected and accelerated’ (Efron, 1987), a process believed to improve the accuracy of confidence intervals (Briggs, 2006). All 95 per cent confidence intervals reported in the current study are bias corrected and accelerated. Put simply, the PASW output of this test provides 2 values (a lower and upper limit) between which a given effect is likely (with 95 per cent confidence) to lie in the original sample. If the value of zero is *not* contained within these two

values, this would suggest a given effect is statistically significant (i.e. the size of the effect is not zero)

It is important to note that the estimates of specific indirect effects (i.e. the indirect effect attributable to a single mediator) are calculated conditional on the presence of other mediators in the model. The values therefore pertain to that mediator's *unique* indirect effect beyond that accounted for by the other mediators. Each estimated effect would, therefore, be different if competing mediators in the model were changed.

The output obtained from Preacher and Hayes's (2008) macros also provides a list of pair-wise contrasts of specific indirect effects, providing 'head to head' comparisons of the relative magnitudes of the indirect effects of two potential mediator variables. These comparisons can be useful in comparing competing theories of mediation, such as the relative specific indirect effects associated with cognitive appraisals and ACT processes in the current study. For each bootstrap resample, contrasts are generated (by subtracting one variables' specific indirect effect from the other), and the sampling distribution of this contrast is generated (by ordering them from high to low as before). Ninety-five per cent confidence intervals are produced to test the null hypothesis, that there is no difference between the two specific indirect effects. If zero is not contained within the 95 per cent confidence intervals, the null hypothesis can be rejected, suggesting a significant difference between the specific indirect effects (i.e. one mediator has a stronger specific indirect than the other).

Directions for downloading PASW macro (the software necessary to carry out multiple mediation analysis) was obtained from Preacher and Hayes (2008).

## **2.6. Ethical considerations and approval**

Research packs contained a participant information sheet which was written in easily understandable language, with consideration for the fact that some respondents may

have some degree of cognitive impairment. Information sheets covered important topics in regard to their rights as research participants, including: that they were under no obligation to participate, that returned data would be treated and stored in a confidential manner (with the caveat of informing GPs of potentially significant scores on the HADS), and that they had the option of requesting a copy of research findings. Contact details were also given for the Principal Investigator, so he could be contacted if they required any help in completing the questionnaires, or if they had any questions.

Approval was given for this research to take place by a NHS ethics committee, and local approval was subsequently granted by NHS Fife and NHS Lothian research and development departments (appendix 6.15).

## **3 Results**

### **3.1 Participants**

While 145 individuals returned data, data was usable for only 133 individuals (see section 3.2.1), who served as participants in this study.

The mean age of participants was 49, with a standard deviation (SD) of 10.8 years, and range of 21 to 75. Only three individuals were aged over 65. Seventy-two per cent were female, and 28 per cent male. 55 per cent reported experiencing a relapsing/remitting form of the disease, and 45 per cent a progressive form. The mean time reported since being diagnosed with MS was 11 years (SD = 8.5). In terms of relational status, 79 per cent were married or cohabiting, 13 per cent separated or divorced, 7 per cent single, and 1 per cent widowed. A majority of participants were recruited from FRS (87 per cent), 11 per cent from CRABIS, and just 1 per cent from each of SBIRS and DCN.

### **3.2 Preliminary data exploration**

#### **3.2.1 Treatment of missing data**

While no consensus view exists on what proportion of missing data on a single variable merits its exclusion from analysis, Cohen and Cohen (1983; as cited in Fox-Wasylyshyn & El-Masri, 2005) recommend that up to 10 per cent missing data is not extensive, below this threshold it is appropriate for the variable to remain in analysis, and for the missing data to be treated (Fox-Wasylyshyn & El-Masri, 2005). No variable had more than 2.9 per cent (or four data points) of data missing, so all variables were retained for treatment.

Data was returned from 145 individuals for this study. Of these, eight individuals were excluded for missing five or more (5.1 per cent) data points. This conservative cut-off point was chosen to ensure high quality of data. For remaining participants, 'sample mean substitution' was employed, replacing the missing value with the mean for that item across the whole sample (Fox-Wasylyshyn & El-Masri, 2005). Sample mean substitutions were employed for the majority of data primarily because they are readily calculated with commands in PASW. One limitation of replacing missing values with the sample mean is that the variance of a variable can be reduced, which can attenuate correlations with other variables (Roth, 1994). In some circumstances more sophisticated methods for replacing missing data are recommended, such as 'regression imputation', which involves using individuals' scores from other variables to predict missing values through regression analysis (Raymond & Roberts, 1987). Previous research has suggested, however, that sample mean substitution tends to provide good representations of the original data as long the percentage of data points missing for an item is low, i.e. less than 10 per cent (Donner, 1982; as cited in Roth, 1994), or even 20 per cent (Downey & King, 1998). The maximum amount of data missing for any item in the current dataset was 2.9 per cent, which combined with the relatively large sample size, would suggest sample mean substitutions would be unlikely to adversely affect the quality of data. In the interest of thoroughness, descriptive statistics were carried out on the data set before and after conducting sample mean substitutions. This analysis showed that conducting sample mean substitutions made negligible differences to mean values and standard deviations for all variables. Simple mean imputations (discussed below) would have been a viable alternative to the use of sample means, though this would have been a moderately more labour intensive procedure since such commands are not available in PAWS.

Missing data for the HADS had to be treated separately, because this was the only scale for which each individual data point was not entered into PASW, only the total scores for the anxiety and depression subscales were entered. Scoring was carried out manually for the HADS due to practicalities surrounding the reporting of scores to GPs. Four respondents were excluded for missing the HADS entirely (it was the final

page of the questionnaire pack). Four individuals missed either one or two data points on a HADS subscale (each subscale has seven items). In these instances, simple mean imputations were calculated, which involves replacing missing values with the mean of the available items on that subscale for the given respondent (Chavance, 2004). This technique is recommended as being appropriate when the proportion of observable data points exceeds 50 per cent (Ware *et al.*, 1980; as cited in Chavance, 2004), a condition which was met for all four relevant individuals.

### **3.2.2 Descriptive Statistics**

Descriptive statistics were calculated to give the mean, SD, median and mode for the totals of the measures, as shown below in Table 1. For those measures which showed relatively high SDs in relation to mean values, median and inter-quartile ranges are also reported.



**Table 1: Descriptive statistics for the questionnaires**

| Measure                    | Mean  | Standard Deviation (SD) | Range of scores obtained |         | Median | Inter-quartile range |
|----------------------------|-------|-------------------------|--------------------------|---------|--------|----------------------|
|                            |       |                         | Maximum                  | Minimum |        |                      |
| MSIS-physical              | 64.49 | 17.60                   | 100                      | 20      | -      | -                    |
| ICQ-helplessness           | 15.18 | 4.94                    | 24                       | 6       | -      | -                    |
| ICQ- perceived benefits    | 13.84 | 4.42                    | 24                       | 6       | -      | -                    |
| IPQ-personal control       | 3.40  | 2.68                    | 10                       | 0       | 3      | 1, 5                 |
| IPQ-concern                | 6.12  | 2.97                    | 10                       | 0       | 6      | 4, 9                 |
| IPQ-understanding          | 7.23  | 2.39                    | 10                       | 0       | 8      | 5, 9                 |
| MSAQ-willingness           | 35.13 | 9.95                    | 57                       | 12      | -      | -                    |
| MSAQ-activities engagement | 50.38 | 13.55                   | 77                       | 11      | -      | -                    |
| MSAQ-total                 | 85.43 | 19.50                   | 128                      | 36      | -      | -                    |
| CFQ                        | 38.77 | 13.04                   | 74                       | 12      | -      | -                    |
| HADS- anxiety              | 7.27  | 4.88                    | 20                       | 0       | 7      | 3, 11                |
| HADS- depression           | 6.58  | 3.93                    | 18                       | 0       | 6      | 3.5, 9               |
| HADS- total                | 13.81 | 8.11                    | 37.00                    | 0       | 12     | 7.25, 19             |
| SWLS                       | 18.93 | 7.55                    | 35                       | 5       | -      | -                    |

Closer analysis showed that for the HADS, 42 per cent of participants scored eight or above on the anxiety subscale, and 38 per cent scored eight or above on the depression subscale, suggesting they may have been experiencing clinically significant symptoms of anxiety and depression respectively. GPs were informed of these scores accordingly. While norms available for the HADS in a MS population are limited, one study conducted by Dahl *et al.* (2009) explored possible ‘caseness’ of anxiety and depression in a MS population (using the same cut off scores on the HADS as the current study). It was found that 30.2 per cent of participants scored eight or above on the anxiety subscale, and 25.6 per cent scored eight or above on the depression subscale. This finding would suggest that levels of psychological distress may have been somewhat elevated in the current sample compared to other MS populations, though the results obtained by Dahl *et al.* (2009) were obtained in Norway (with a Norwegian version of the HADS), so a variety of factors could be responsible for differences.

The mean of 64.49 (SD = 17.6) on the MSIS- physical for the sample is only slightly larger than the value of 61.0 (SD = 20.3) obtained by Hobart *et al.* (2004) in a large sample ( $N = 751$ ) of members of the ‘Multiple Sclerosis Society’. This difference may be attributable to the current sample inherently including more individuals in need of some variety of professional input. Alternatively, the relatively high levels of depressive symptoms among the sample could have inflated perceptions of physical symptoms.

The mean score of 38.77 (SD = 13.04) on the CFQ is close to the mean value of 40.2 (SD = 11.04) obtained from non-clinical samples ( $N = 893$ ), and appears substantially lower than the mean value of 59.7 (SD = 12.1) reported from a sample ( $N = 171$ ) of individuals suffering from psychological disorders (Gillanders *et al.*, 2010).

The mean SWLS score of 18.93 (SD = 7.55) is, unsurprisingly, lower than the mean score of 24.1 (SD = 6.9) obtained from an English adult ( $N = 111$ ) population (Hayes & Joseph, 2003; as cited in Pavot & Diener, 2008). No mean scores are available for

the SWLS in a MS population, but the mean score of 19.7 (SD = 7.9) obtained by Putzke *et al.* (2001; as cited in Pavot & Diener, 2008) for a sample of married individuals with spinal cord injuries ( $N = 53$ ), is similar to the mean score in the current sample.

Unfortunately, Evers *et al.* (2001) did not report mean scores for the ICQ subscales. There is no previous research that reports mean scores for the subscales of the brief-IPQ in a MS population.

### 3.2.3 Reliability of scales

Chronbach's  $\alpha$  values were calculated for the questionnaires to give a measure of internal consistency. These values can be seen below in Table 2.

**Table 2: Internal consistency of questionnaires**

| Measure                    | Number of items in measure | Chronbach's alpha value |
|----------------------------|----------------------------|-------------------------|
| MSIS-physical              | 20                         | .94                     |
| ICQ-helplessness           | 6                          | .91                     |
| ICQ- perceived benefits    | 6                          | .84                     |
| MSAQ-willingness           | 9                          | .79                     |
| MSAQ-activities engagement | 11                         | .89                     |
| MSAQ-total                 | 20                         | .87                     |
| CFQ                        | 13                         | .85                     |
| SWLS                       | 5                          | .85                     |

While no definite 'cut-off' value exists for Chronbach's  $\alpha$ , a value of .7 to .8 is generally considered acceptable (Field, 2009). Table 2 shows that all scales used in the current study, including the newly adapted MSAQ, showed acceptable levels of reliability. Values for the HADS could not be calculated, because only subscale total

scores were entered into PASW. Chronbach's  $\alpha$  could not be calculated for the IPQ subscales, because they are single item scales.

While  $\alpha$  values are reported in Table 2 for the MSAQ subscales, and the total score (comprised of the two subscales added together), in further analysis the MSAQ total score will be used, and referred to simply as the MSAQ. It was deemed appropriate to use the total score as a complete measure of MS related 'acceptance'.

### 3.2.4 Testing the normality of data

While the multiple mediation techniques employed in the current study do not make parametric assumptions (as they are based on regression coefficients), the techniques employed in more preliminary analysis (Pearson correlations and independent sample t-tests) do require data to be normally distributed. Values of skewness and kurtosis, along with their respective standard error (SE), were obtained from descriptive statistics and converted to z-scores using the following formulae (Field, 2009):

$$\begin{aligned} \text{Z score for skewness} &= \frac{\text{value for skewness}}{\text{standard error of skewness}} \\ \text{Z score for kurtosis} &= \frac{\text{value for kurtosis}}{\text{standard error of kurtosis}} \end{aligned}$$

Z-score values of greater than +/- 1.96 suggest that the data for a given measure is significantly differently (at the  $p < .05$  level) from a normal distribution. The z-score values for skew and kurtosis across all continuous measures used in this study can be seen in Appendix 6.16. The following measures produced z-score values which suggested they were not normally distributed: IPQ- understanding, MSAQ- engagement, AAQ-II, HADS, and 'years since diagnosis'. Square-root

transformations were carried out on these measures, as described by Field (2009), the z-score values for which are also shown in Appendix 6.16. Z-score values suggested that the transformed data for MSAQ-engagement, HADS, and ‘years since diagnosis’ were normally distributed, so these transformed variables were used in all further parametric analysis. The AAQ-II, however, did not appear normally distributed after square-root transformation (or after ‘log’ or ‘reciprocal’ transformations). Hence, all correlations reported for the AAQ-II (in sections 2.3.4. and 2.3.6.) use the non-parametric Spearman’s correlation.

### **3.2.5 Testing for possible covariance between demographic and dependent variables**

Analysis was conducted to ascertain whether any of the demographic variables related to scores on the dependent variables (DVs). If demographic variables were found to be related to either DV, they would need to be included as covariates in mediational analyses to control for their effects.

#### **3.2.5.1      *Assessment of ‘age’ and ‘years since diagnosis’ as possible covariates***

For demographic variables represented with interval data, Pearson correlations were calculated between them and the DVs, as shown in Table 3.

**Table 3: Pearson correlations between demographic variables (age, years since diagnosis) and dependent variables.**

|                              |                     | Dependent/Outcome variables |      |
|------------------------------|---------------------|-----------------------------|------|
|                              |                     | HADS                        | SWLS |
| <b>Age</b>                   | Pearson correlation | .08                         | -.16 |
|                              | Significance        | .35                         | .03* |
| <b>Years since diagnosis</b> | Pearson correlation | .03                         | -.18 |
|                              | Significance        | .75                         | .03* |

\* Correlation is significant at  $p < 0.05$  level (2-tailed)

Table 3 shows that none of the demographic variables correlated significantly with the HADS, so did not require inclusion as covariates in analysis involving the HADS.

‘Age’ and ‘years since diagnosis’ both showed small, and statistically significant, correlations with the SWLS, supporting their inclusion as covariates in mediational analysis involving the SWLS.

The demographic variables of ‘type of disease’, ‘gender’ and ‘relational status’ were represented as categorical variables, so their relationship with scores on the DVs were investigated with independent samples t-tests, as follows. Mean values and SE reported for the HADS are based on the square-root transformed data, so are lower in value than total HADS scores pre-transformation.

### **3.2.5.2 Assessment of ‘type of disease’ as a possible covariate**

Individuals with a relapsing/remitting form of MS ( $M = 20.58$ ,  $SE = 0.94$ ) tended to score significantly higher on the SWLS compared to individuals reporting a progressive form ( $M = 16.96$ ,  $SE = 0.97$ ) of the disease,  $t(116) = 2.68$ ,  $p < .01$ . This

result suggested that ‘type of disease’ required inclusion as a covariate in mediational analysis involving the SWLS.

In the case of the HADS, individuals with a relapsing/remitting form of MS ( $M = 3.44$ ,  $SE = 0.14$ ) showed no significant differences in their scores compared with individuals reporting a progressive form ( $M = 3.52$ ,  $SE = 0.16$ ) of the disease,  $t(115) = -0.36$ ,  $p = .72$ . This result suggested that ‘type of disease’ did not required inclusion as a covariate in mediational analysis involving the HADS.

### **3.2.5.3      *Assessment of ‘gender’ as a possible covariate***

While male participants ( $M = 17.53$ ,  $SE = 1.13$ ) tended to score slightly lower on the SWLS compared to female participants ( $M = 19.62$ ,  $SE = 0.78$ ), this difference was not statistically significant,  $t(130) = -1.44$ ,  $p > .05$ . There was also no significant difference between male ( $M = 3.67$ ,  $SE = 0.16$ ) and female ( $M = 3.46$ ,  $SE = 0.12$ ) participants’ scores on the HADS,  $t(129) = 0.94$ ,  $p = .35$ . These results suggested that ‘gender’ did not require inclusion as a covariate in mediational analysis for the SWLS or the HADS.

### **3.2.5.4      *Assessment of ‘relational status’ as a possible covariate***

Regarding their relational status, participants rated themselves as belonging to one of four categories: ‘married or co-habiting’, ‘separated or divorced’, ‘single’, or ‘widowed’. A vast majority (79 per cent) of participants were married or co-habiting, while relatively low numbers were in the other three groups (see section 3.1.1.). For independent samples t-tests to be conducted, these three smaller grouping were combined into one group, which shall hereon be referred to as ‘single’.

Participants who were married or co-habiting ( $M = 19.56$ ,  $SE = 0.75$ ) tended to score slightly higher than those who were single ( $M = 17.00$ ,  $SE = 1.15$ ) on the SWLS, but this difference was not significant,  $t(130) = -1.59$ ,  $p = 0.13$ . There were no

significant differences in HADS scores between participants who were married or co-habiting ( $M = 3.53$ ,  $SE = 0.11$ ) and those who were single ( $M = 3.47$ ,  $SE = 0.26$ ),  $t(129) = -0.23$ ,  $p = .82$ .

These results suggested that ‘relational status’ did not require inclusion as a covariate in mediational analysis

#### **3.2.5.5      *Summary of analysis for potential covariance between demographic and dependent variables***

Results suggested that ‘age’, ‘type of disease’, and ‘years since diagnosis’ would be appropriate covariates in mediational analysis with the SWLS serving as dependent variable, while no demographic variables were required as covariates in mediational analysis with the HADS as dependent variable.

#### **3.2.6    Testing for possible collinearity between predictor variables**

Pearson correlations were calculated between all predictor variables to test for multicollinearity, as shown in Table 4. Field (2009) recommends that very high correlations (i.e. of above approximately .9) may indicate significant collinearity between variables, which would be a contra-indicator for their inclusion in the same mediational analysis (Preacher & Hayes, 2008).



**Table 4: Pearson correlations among predictor variables**

|                               |                     | <b>MSIS-physical</b> | <b>ICQ-helplessness</b> | <b>ICQ-perceived benefits</b> | <b>IPQ-personal control</b> | <b>IPQ-concern</b> | <b>IPQ-understanding</b> | <b>MSAQ</b>   | <b>CFQ</b>    |
|-------------------------------|---------------------|----------------------|-------------------------|-------------------------------|-----------------------------|--------------------|--------------------------|---------------|---------------|
| <b>MSIS-physical</b>          | Pearson correlation | 1                    | <b>.71**</b>            | .01                           | <b>-.29**</b>               | <b>.28**</b>       | .12                      | <b>-.41**</b> | <b>.25**</b>  |
|                               | Significance        |                      | <b>.00</b>              | .837                          | <b>.00</b>                  | <b>.00</b>         | .17                      | <b>.00</b>    | <b>.00</b>    |
| <b>ICQ-helplessness</b>       | Pearson correlation |                      | 1                       | 0.07                          | <b>-.34**</b>               | <b>.53**</b>       | -.01                     | <b>-.62**</b> | <b>.47**</b>  |
|                               | Significance        |                      |                         | .38                           | <b>.00</b>                  | <b>.00</b>         | .92                      | <b>.00</b>    | <b>.00</b>    |
| <b>ICQ-perceived benefits</b> | Pearson correlation |                      |                         | 1                             | <b>.23**</b>                | .04                | <b>.24*</b>              | .13           | -.09          |
|                               | Significance        |                      |                         |                               | <b>.00</b>                  | .63                | <b>.00</b>               | .12           | .27           |
| <b>IPQ-personal control</b>   | Pearson correlation |                      |                         |                               | 1                           | -.05               | .11                      | <b>.32**</b>  | <b>-.27**</b> |
|                               | Significance        |                      |                         |                               |                             | .49                | .20                      | <b>.00</b>    | <b>.00</b>    |
| <b>IPQ-concern</b>            | Pearson correlation |                      |                         |                               |                             | 1                  | -.02                     | <b>-.51**</b> | <b>.35**</b>  |
|                               | Significance        |                      |                         |                               |                             |                    | .84                      | <b>.00</b>    | <b>.00</b>    |
| <b>IPQ-understanding</b>      | Pearson correlation |                      |                         |                               |                             |                    | 1                        | .17           | <b>-.19*</b>  |
|                               | Significance        |                      |                         |                               |                             |                    |                          | .19           | <b>.03</b>    |
| <b>MSAQ</b>                   | Pearson correlation |                      |                         |                               |                             |                    |                          | 1             | <b>-.59**</b> |
|                               | Significance        |                      |                         |                               |                             |                    |                          |               | <b>.00</b>    |
| <b>CFQ</b>                    | Pearson correlation |                      |                         |                               |                             |                    |                          |               | 1             |
|                               | Significance        |                      |                         |                               |                             |                    |                          |               |               |

\* denotes significance at  $p < .05$  level (2-tailed)

\*\* denotes significance at  $p < .01$  level (2-tailed)

Table 4 shows, with statistically significant correlations emboldened, that no correlations between predictor variables were high enough to suggest problems with collinearity. The highest correlation existed between the ICQ-helplessness and the MSIS-physical ( $r = .71, p < .001$ ). All the measures that correlated significantly with one another did so in theoretically predictable directions.

Encouragingly, the MSAQ demonstrated theoretically consistent relationships with other measures: correlating positively with IPQ- personal control ( $r = .32, p < .001$ ), and correlating negatively with higher scores on ICQ-helplessness ( $r = -.62, p < .001$ ), IPQ-concern ( $r = -.51, p < .001$ ), and the CFQ ( $r = -.59, p < .001$ ). It also showed a small positive correlation with ICQ-perceived benefits, though it did not reach statistical significance ( $r = .13, p = .12$ ). The MSAQ willingness and activities engagement subscales demonstrated moderate correlations with each other ( $r = .33, p < .001$ ).

With the single exception of ICQ-perceived benefits, the CFQ showed significant correlations with every measure in expected directions, including the MSAQ.

Overall, the results from correlational analysis supported the inclusion of all predictor variables in mediational analysis.

### **3.2.7 Correlations among potential predictor variables and dependent variables**

Predictors in a mediation analysis, or regression analysis, should demonstrate strong correlations with the DVs. If a potential predictor shows significant correlations with other predictors, but not with the DVs, it could potentially suppress the effects of other predictors without demonstrating an additional specific indirect effect itself. Pearson correlations were carried out between all potential predictor variables, and the DVs, as shown in Table 5.

**Table 5: Pearson correlations between predictor variables and dependent variables**

|                               |                     | Dependent/outcome variables |               |
|-------------------------------|---------------------|-----------------------------|---------------|
|                               |                     | HADS                        | SWLS          |
| <b>MSIS-physical</b>          | Pearson correlation | <b>.32**</b>                | <b>-.46**</b> |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |
| <b>ICQ-helplessness</b>       | Pearson correlation | <b>.43**</b>                | <b>-.54**</b> |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |
| <b>ICQ-perceived benefits</b> | Pearson correlation | -.11                        | <b>.27**</b>  |
|                               | Significance        | .19                         | <b>.00</b>    |
| <b>IPQ-personal control</b>   | Pearson correlation | <b>-.35**</b>               | <b>.33**</b>  |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |
| <b>IPQ-concern</b>            | Pearson correlation | <b>.36**</b>                | <b>-.29**</b> |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |
| <b>IPQ-understanding</b>      | Pearson correlation | -.16                        | .09           |
|                               | Significance        | .07                         | .30           |
| <b>MSAQ</b>                   | Pearson correlation | <b>-.62**</b>               | <b>.66**</b>  |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |
| <b>CFQ</b>                    | Pearson correlation | <b>.75**</b>                | <b>-.51**</b> |
|                               | Significance        | <b>.00</b>                  | <b>.00</b>    |

\* denotes significance at  $p < .05$  level (2-tailed)

\*\* denotes significance at  $p < .01$  level (2-tailed)

Statistically significant correlations are shown in bold in Table 5. It is evident from Table 5 that almost all potential predictor variables correlated significantly with DVs, with three exceptions: ICQ-perceived benefits and IPQ- understanding did not correlate significantly with the HADS, and IPQ-understanding did not correlate significantly with the SWLS. It was, therefore, decided that ICQ-perceived benefits would not be included in mediational analysis with the HADS as DV, and IPQ-understanding would not be included in mediational analysis with the SWLS as DV. Since the correlation between the HADS and IPQ- understanding failed to reach the

$p < .05$  level of statistical significance by a relatively narrow margin ( $r = -.16$ ,  $p = .068$ ), it was decided that it would still be included in mediational analysis with the HADS as DV. Later supplemental analysis (see section 3.3.4.2.) showed that excluding the IPQ- understanding would have made no meaningful difference to the results and conclusions of eventual mediational analysis.

### **3.2.8 Testing assumptions of regression analysis**

Since the mediation analysis (Preacher & Hayes, 2008) employs regression coefficients, it was considered prudent in the interest of thoroughness to test whether the data met the assumptions of regression analysis.

Many of the assumptions of regression analysis described by Berry (1993; as cited in Field, 2009) were obviously met by the current study without additional analysis, including: use of appropriate variable types, non-zero variance in predictors, no perfect multicollinearity (see section 3.2.4.), and independence (i.e. each value of the DV comes from a separate entity).

To test the assumptions of homoscedasticity and linearity, independence of errors (i.e. residual terms are uncorrelated), and normal distribution of error, additional analyses were necessary, as described by Field (2009). To access necessary commands in PASW, linear regression analyses were conducted: one with the HADS as DV, and one with the SWLS as DV. Inspection of scatter-plots (regression standardised residuals vs. regression predicted value) confirmed that the data met the assumptions of homoscedasticity and linearity. Values of the Durbin-Watson test confirmed independence of errors, with values close to 2 for the HADS (2.12) and SWLS (2.07). Inspection of histograms of standardised residuals, and normal probability plots, supported the assumption of normality of residuals.

While all assumptions of regression were met, it is debatable whether this is actually required for the Preacher and Hayes' (2008) method of mediational analysis. Most of

the assumptions exist to enable the use of estimated standard errors to construct confidence intervals and test statistical significance using normal theory (Shrout & Bolger, 2002), procedures which are not required for bootstrapping (K. Preacher, personal communication, 12 July 2011).

### 3.3 Testing of research hypotheses with multiple mediation analyses

#### 3.3.1 Mediation analysis with HADS as dependent variable

Preacher and Hayes's (2008) macro was used to analyse a multiple mediation model with the following variables:

|                              |                       |
|------------------------------|-----------------------|
| <b>Independent variable:</b> | MSIS-physical         |
| <b>Mediator variables:</b>   | ICQ-helplessness      |
|                              | CFQ                   |
|                              | MSAQ                  |
|                              | IPQ- personal control |
|                              | IPQ- concern          |
|                              | IPQ- understanding    |
| <b>Dependent variable:</b>   | HADS                  |

No covariates were necessary for this analysis (see section 3.2.5.). Results are based on bootstrapping, using 5000 re-samples.

The indirect effects in this mediation analysis can be seen in Table 6. The two columns furthest to the right of Table 6 show bias corrected and accelerated 95 per cent confidence intervals, hereon referred to simply as 95 per cent CIs. 95 per cent CIs which *do not contain zero* between them are marked in bold, because in such instances it can be stated with 95 per cent confidence that a given mediation effect is not zero (i.e. it is significant).

**Table 6: Results of multiple mediation analysis with HADS as dependent variable: Indirect effects of potential mediators**

|                       | Point estimate of indirect effect from bootstrapping | Standard error (SE) | BCa 95% confidence intervals |              |
|-----------------------|--|---------------------|------------------------------|--------------|
|                       |  |                     | Lower                        | Upper        |
| ICQ-helplessness      | -.0558   | .0367               | -.1251                       | .0190        |
| CFQ                   | .0654  | .0269               | <b>.0200</b>                 | <b>.1264</b> |
| MSAQ                  | .0433  | .0190               | <b>.0105</b>                 | <b>.0867</b> |
| IPQ-personal control  | .0157  | .0101               | <b>.0002</b>                 | <b>.0400</b> |
| IPQ- concern          | .0105  | .0121               | -.0100                       | .0386        |
| IPQ-understanding     | -.0019   | .0044               | -.0178                       | .0030        |
| Total indirect effect | .0772  | .0444               | -.0076                       | .1662        |

### **3.3.1.1. Performance of the model as a whole**

A model summary (treating the model as a linear regression) produced an adjusted  $R^2 = .61$ , suggesting that the 8 predictor variables accounted for 61 per cent of variance in the HADS. The F-ratio for the model reached statistical significance,  $F_{(7, 117)} = 28.43, p < .001$ , suggesting the model accounts for significant proportions of the variance in HADS scores.

The total and direct effects of the MSIS-physical on the HADS were found to be .12,  $p < .01$ , and .04,  $p > .05$  respectively. As shown in Table 6, the total indirect effect through the mediators (the difference between the total and direct effects) had a point estimate of .0772, with 95 per cent CIs of -.0076 to .1662. Since these CIs cross zero, the total indirect effect does not appear significant. This is not problematic, as stated by Preacher and Hayes (2008), ‘It is entirely possible to find specific indirect effects to be significant in the presence of a nonsignificant total direct effect’ (p.882). In

such instances, it is possible that the relatively low magnitudes of specific indirect effects associated with certain variables are lowering the overall performance of the model, despite some variables having stronger specific indirect effects associated with them.

#### **3.3.1.2.        *Specific indirect effects of mediating variables***

As their 95 per cent CIs do not encompass zero, the CFQ, MSAQ, and IPQ-personal control appear to be the only significant mediators of the relationship between symptoms of MS and psychological distress, as measured with the HADS.

Table 7 shows the results of pair-wise contrasts of specific indirect effects for analysis with the HADS as DV. As explained in section 2.5.3., these are ‘head to head’ comparisons of the relative magnitudes of the indirect effects of two potential mediator variables. Contrasts for which 95 per cent CIs do not contain zero are shown in bold, suggesting that these contrast are statistically significant, with one mediator having a stronger specific indirect effect than the other.



**Table 7: Results of multiple mediation analysis with HADS as dependent variable: Contrasting the specific indirect effects of different mediating variables**

|  | Point estimate of difference in effect between potential mediators | Standard error (SE) | BCa 95% confidence intervals |               |
|--|--|---------------------|------------------------------|---------------|
|  |  |                     | Lower                        | Upper         |
| ICQ-helplessness vs. CFQ                     | -.1212   | .0485               | <b>-.2195</b>                | <b>-.0321</b> |
| ICQ-helplessness vs. MSAQ                    | -.0991   | .0428               | <b>-.1845</b>                | <b>-.0162</b> |
| ICQ- helplessness vs. IPQ- personal control  | -.0715   | .0403               | -.1484                       | .0080         |
| ICQ-helplessness vs. IPQ- concern            | -.0663   | .0441               | -.1498                       | .0208         |
| ICQ-helplessness vs. IPQ- understanding      | -.0539   | .0369               | -.1230                       | .0211         |
| CFQ vs. MSAQ                                 | .0221  | .0310               | -.0303                       | .0947         |
| CFQ vs. IPQ personal control                 | .0498  | .0273               | <b>.0061</b>                 | <b>.1150</b>  |
| CFQ vs. IPQ- concern                         | .0549  | .0280               | <b>.0054</b>                 | <b>.1177</b>  |
| CFQ vs. IPQ- understanding                   | .0673  | .0266               | <b>.0207</b>                 | <b>.1268</b>  |
| MSAQ vs. IPQ- personal control               | .0276  | .0213               | -.0123                       | .0726         |
| MSAQ vs. IPQ- concern                        | .0328  | .0256               | -.0160                       | .0860         |
| MSAQ vs. IPQ- understanding                  | .0451  | .0186               | <b>.0128</b>                 | <b>.0873</b>  |
| IPQ-personal control vs. IPQ- concern        | .0052  | .0135               | -.0217                       | .0329         |
| IPQ- personal control vs. IPQ- understanding | .0175  | .0107               | -.0003                       | .0418         |
| IPQ-concern vs. IPQ- understanding           | .0123  | .0132               | -.0111                       | .0410         |

#### **3.3.1.3.      *Pair-wise contrasts of specific indirect effects***

As shown in Table 7, six pair-wise contrasts appear to be statistically significant. The CFQ showed a significantly larger specific indirect effect than: ICQ-helplessness, IPQ-personal control, IPQ-concern, and IPQ-understanding. The MSAQ demonstrated significantly larger specific indirect effects than ICQ- helplessness and IPQ- understanding. These results will be discussed further in section 3.3.3.

#### **3.3.1.4.      *Assessing Hypothesis 1***

**Cognitive appraisals will mediate the relationship between MS symptoms and symptoms of psychological distress.**

The results show relatively minimal support for hypothesis 1. ICQ- helplessness, IPQ-concern, and IPQ-understanding failed to show evidence of mediating the relationship between MS symptoms and symptoms of psychological distress. Of all measures of cognitive appraisal, only IPQ- personal control showed evidence of being a significant mediator of the relationship between MS symptoms and symptoms of psychological distress. While the 95 per cent CIs for the specific indirect effect of the IPQ-personal control did not encompass zero, the lower level limit (.0002) only missed zero very narrowly.

#### **3.3.1.5.      *Assessing Hypothesis 2***

**ACT processes will mediate the relationship between MS symptoms and symptoms of psychological distress.**

The results clearly support hypothesis 2. The CFQ and MSAQ appeared to be the strongest mediators of the relationship between MS symptoms and symptoms of psychological distress. Both demonstrated significant specific indirect effects.

### 3.3.2 Mediation analysis with SWLS as dependent variable

Preacher and Hayes's (2008) macro was used to analyse a multiple mediation model with the following variables:

|                              |                         |
|------------------------------|-------------------------|
| <b>Independent variable:</b> | MSIS-physical           |
| <b>Mediator variables:</b>   | ICQ-helplessness        |
|                              | ICQ- perceived benefits |
|                              | CFQ                     |
|                              | MSAQ                    |
|                              | IPQ- personal control   |
|                              | IPQ- concern            |
| <b>Dependent variable:</b>   | SWLS                    |
| <b>Covariates:</b>           | Age                     |
|                              | Type of disease         |
|                              | Years since diagnosis   |

The indirect effects in this mediation analysis can be seen in Table 8. Results are based on bootstrapping, using 5000 re-samples.

**Table 8: Results of multiple mediation analysis with SWLS as dependent variable: Indirect effects of potential mediators**

|                        | Point estimate of indirect effect from bootstrapping | Standard error (SE) | BCa 95% confidence intervals |               |
|------------------------|--|---------------------|------------------------------|---------------|
|                        |  |                     | Lower                        | Upper         |
| ICQ-helplessness       | -.0332   | .0395               | -.1128                       | .0436         |
| ICQ-perceived benefits | .0042  | .0100               | -.0313                       | .0283         |
| CFQ                    | -.0202   | .0148               | -.0620                       | .0000         |
| MSAQ                   | -.0642   | .0230               | <b>-.1140</b>                | <b>-.0228</b> |
| IPQ-personal control   | -.0067   | .0091               | -.0302                       | .0072         |
| IPQ- concern           | -.0035   | .0113               | -.0191                       | .0264         |
| Total indirect effect  | -.1165   | .0427               | <b>-.1988</b>                | <b>-.0322</b> |

### 3.3.2.1. Performance of the model as a whole

A model summary produced an adjusted  $R^2 = .51$ , suggesting that the 8 predictor variables and 3 covariates accounted for 51 per cent of variance in the SWLS. The F-ratio for the model reached statistical significance,  $F_{(10, 99)} = 12.31, p < .001$ , suggesting the model accounts for significant proportions of the variance in SWLS scores.

The total and direct effects of the MSIS-physical on the SWLS were found to be  $-.17, p < .001$ , and  $.06, p > .05$  respectively. As shown in Table 6, the total indirect effect through the mediators (the difference between the total and direct effects) had a point estimate of  $-.1165$ , with 95 per cent CIs of  $-.1988$  to  $-.0322$ . These CIs do not cross zero, suggesting a significant total indirect effect.

### **3.3.2.2.      *Specific indirect effects of mediating variables***

Table 8 shows that the MSAQ was the only mediator that clearly demonstrated a statistically significant specific indirect effect. The upper limit of the 95 per cent CI for the CFQ was exactly on zero, suggesting it is borderline whether or not the CFQ should be considered a significant mediator of the relationship between MS symptoms and satisfaction with life.

None of the measures of cognitive appraisals demonstrated statistically significant specific indirect effects.

Table 7 shows the results of pair-wise contrasts of specific indirect effects for analysis with the SWLS as DV.

**Table 9: Results of multiple mediation analysis with SWLS as dependent variable: Contrasting the specific indirect effects of different mediating variables**

|  | Point estimate of difference in effect between potential mediators | Standard error (SE) | BCa 95% confidence intervals |               |
|--|--|---------------------|------------------------------|---------------|
|  |  |                     | Lower                        | Upper         |
| ICQ-helplessness vs. ICQ perceived benefits      | -.0373   | .0412               | -.1170                       | .0439         |
| ICQ-helplessness vs. CFQ                         | -.0130   | .0442               | -.0950                       | .0786         |
| ICQ- helplessness vs. MSAQ                       | .0310  | .0487               | -.0640                       | .1276         |
| ICQ-helplessness vs. IPQ- personal control       | -.0265   | .0420               | -.1082                       | .0572         |
| ICQ-helplessness vs. IPQ- concern                | -.0367   | .0429               | -.1214                       | .0479         |
| ICQ-perceived benefits vs. CFQ                   | .0243  | .0173               | -.0044                       | .0646         |
| ICQ-perceived benefits vs. MSAQ                  | .0683  | .0231               | <b>.0251</b>                 | <b>.1164</b>  |
| ICQ-perceived benefits vs. IPQ- personal control | .0108  | .0125               | -.0105                       | .0393         |
| ICQ-perceived benefits vs. IPQ- concern          | .0007  | .0146               | -.0296                       | .0288         |
| CFQ vs. MSAQ                                     | .0440  | .0287               | -.0131                       | .1017         |
| CFQ vs. IPQ- personal control                    | -.0135   | .0174               | -.0579                       | .0141         |
| CFQ vs. IPQ- concern                             | -.0236   | .0192               | -.0697                       | .0081         |
| MSAQ vs. IPQ-personal control                    | -.0575   | .0249               | <b>-.1107</b>                | <b>-.0132</b> |
| MSAQ vs. IPQ- concern                            | -.0676   | .0276               | <b>-.1248</b>                | <b>-.0156</b> |
| IPQ- personal control vs. IPQ-concern            | -.0101   | .0134               | -.0397                       | .0145         |

### **3.3.2.3.      *Pair-wise contrasts of specific indirect effects***

As shown in bold in Table 8, only three pair-wise comparisons of specific indirect effects appeared statistically significant, each one involving the MSAQ. The MSAQ had significantly stronger specific indirect effects associated with it compared to ICQ- perceived benefits, IPQ-personal control, and IPQ- concern. These results will be discussed further in section 3.3.3.

### **3.3.2.4.      *Assessing Hypothesis 3***

**Cognitive appraisals will mediate the relationship between MS symptoms and satisfaction with life.**

The results do not support hypothesis 3. No measure of cognitive appraisal showed evidence of a statistically significant specific indirect effect on the relationship between MS symptoms and satisfaction with life.

### **3.3.2.5.      *Assessing Hypothesis 4:***

**ACT processes will mediate the relationship between MS symptoms and satisfaction with life.**

The results support hypothesis 4. The MSAQ showed evidence of a statistically significant specific indirect effect on the relationship between MS symptoms and satisfaction with life, while the significance of the specific indirect effect associated with the CFQ is more borderline.

### **3.3.3. Assessing Hypothesis 5:**

**In comparison to cognitive appraisals, ACT processes will tend to be stronger mediators of the relationship between MS symptoms and outcome measures.**

The results of both multiple mediation analyses support hypothesis 5. In analysis with the HADS as DV, all six statistically significant pair-wise comparisons involved one of the ACT measures demonstrating stronger specific indirect effects in comparison to a measure of cognitive appraisal. In analysis with the SWLS as DV, all three significant pair-wise comparisons involved the MSAQ demonstrating stronger specific indirect effects in comparison to measures of cognitive appraisal.

Across all pair-wise comparisons of different mediators, no measure of cognitive appraisal managed to demonstrate significantly stronger specific indirect effects on the relationship between MS symptoms and outcome measure.

### **3.3.4. Supplemental analyses**

#### **3.3.4.1. *A note on inclusion of covariates***

As described in section 3.2.5, variables were only included as covariates in mediational analysis if they showed evidence of impacting upon the DVs. Both mediational analyses were, however, re-run with all five possible covariates included (age, type of disease, years since diagnosis, relational status, and gender), to ensure results were not attributable to the effects of omitted variables.

Including all possible covariates did not alter the results or conclusions of analyses (in terms of overall performances of models, specific indirect effects of mediating variables, or pair-wise contrasts of specific indirect effects) in any meaningful way.



#### **3.3.4.2      *Results of simple mediation analyses***

As previously explained in section 2.5.3.2, for the multiple mediation analysis employed in this study, the specific indirect effects associated with given mediators are conditional on the presence of other mediators in the model (Preacher & Hayes, 2008). The values, therefore, pertain to that mediators' *unique* indirect effect beyond that accounted for by the other mediators. It was thought that it would be informative to run numerous simple mediation analyses (with a single mediator variable per analysis) to ascertain whether proposed mediator variables would appear to be significant mediators themselves, when no other competing variables were present.

Simple mediation analyses were run with the HADS as DV, for each individual mediator variable included in the multiple mediation analysis. With the exception of the IPQ- understanding, every individual mediator variable had a significant indirect effect associated with it (with 95 per cent CIs not crossing zero), suggesting significant mediation of the relationship between MS symptoms and psychological distress.

Similarly, simple mediation analyses were run with the SWLS as DV, for each individual mediator variable included in the original analysis. With the exceptions of IPQ- perceived benefits and IPQ- concern, every individual mediator variable had a significant indirect effect associated with it (with 95 per cent CIs not crossing zero), suggesting significant mediation of the relationship between MS symptoms and satisfaction with life. A summary of results obtained from simple mediation analyses can be seen in appendix 6.17.

Since some potential mediator variables did not appear to be significant mediators of the relationships between MS symptoms and outcome measures when run in simple mediation analyses, the multiple mediation analyses of sections 3.3.1 and 3.3.2 were re-run with them omitted. Their omission did not alter the results or conclusions of

analyses (in terms of overall performances of models, specific indirect effects of mediating variables, or pair-wise contrasts of specific indirect effects of remaining variables) in any meaningful way.

## **4 Discussion**

### **4.1 Interpretation of findings**

#### **4.1.1 Mediation of the relationship between symptoms of MS and psychological distress**

Results suggested that cognitive fusion, as measured by the CFQ, was the strongest mediator (with the highest point estimate of specific indirect effect, and 95 per cent CIs furthest from zero) of the relationship between symptoms of MS and psychological distress. Higher levels of cognitive fusion related to greater psychological distress in response to symptoms of MS. This result is perhaps particularly impressive given that the CFQ is not an illness specific measure, but relates more generally to individuals' tendency to 'fuse' (see section 2.3.5. for elaboration, and appendix 6.5 for full questionnaire) with their thoughts. The MSAQ was the second strongest mediator of the relationship between symptoms of MS and psychological distress, with higher levels of acceptance (i.e. a willingness to experience aversive states in the service of engaging in valued living, see appendix 6.7 for full questionnaire) relating to lower levels of psychological distress in response to symptoms of MS. These findings are consistent with an ACT conceptualisation of psychopathology (Hayes *et al.*, 1999), previous research showing CFQ scores to correlate with psychological distress (Gillanders *et al.*, 2010), and research showing acceptance to be an important process in adjustment to chronic health conditions (see section 1.4.6.2.).

The IPQ- personal control ("How much control do you feel you have over your illness?") was the only measure of cognitive appraisal found to be a significant mediator of the relationship between symptoms of MS and psychological distress, though it appeared to be a weaker mediator than the ACT measures (with a lower point estimate of specific indirect effect, and 95 per cent CIs closer to zero). The

other measures of cognitive appraisal were not found to be significant mediators. In the cases of ICQ- helplessness and IPQ-concern, they became non-significant in multiple mediation analysis (when the indirect effect they shared with other mediators was taken into account), while they appeared to be significant mediators of the relationship between symptoms of MS and psychological distress when run alone in simple mediation analysis (see section 3.3.4.2). IPQ- understanding was not a significant mediator of the relationship between symptoms of MS and psychological distress, even when run as sole mediator in a simple mediation analysis.

It is an interesting finding that IPQ- personal control was the only significant mediator among the appraisal measures. Perceptions of personal control over internal and external states have been highlighted as predictive of mental health, even in the absence of any actual control (Skinner, 1995). As outlined earlier (see section 1.4.5.3.), Arch and Craske (2008) have discussed that while ACT does not advocate attempts to control internal states, it is possible that ACT interventions (which involve ceasing attempts at control in favour of fully engaging with ones' current experience) may have the somewhat paradoxical effect of increasing feelings of personal control and predictability of symptoms. The relationship between perceptions of personal control and ACT constructs may be an area worthy of further study. For example, individuals may feel they have more control over their illness with higher levels of acceptance. Indeed, IPQ-personal control and MSAQ are moderately correlated ( $r = .32, p > .001$ ).

#### **4.1.2 Mediation of the relationship between symptoms of MS and satisfaction with life**

Results suggested that acceptance, as measured by the MSAQ, was the strongest mediator (with the highest point estimate of specific indirect effect, and 95 per cent CIs furthest from zero) of the relationship between symptoms of MS and satisfaction with life. Higher levels of acceptance related to greater satisfaction with life in the face of symptoms of MS. Interpretation of the specific indirect effect of the CFQ is more difficult, because the upper 95 per cent CI was exactly zero. With this result

being on the absolute borderline of statistical significance, it appears likely that cognitive fusion may also be a mediator of the relationship between symptoms of MS and satisfaction with life, with higher levels of cognitive fusion relating to lower satisfaction with life in the face of symptoms of MS.

It appears theoretically coherent that acceptance should be the strongest mediator in analysis with the SWLS as DV. Satisfaction with life, as a concept, is related to 'valued living' in ACT. The rationale of cultivating acceptance in ACT is to facilitate the living of one's life in accordance with chosen values. The findings support the notion that in endeavouring to live a satisfying life while experiencing symptoms of MS, it is adaptive to be willing to experience difficult thoughts and feelings in regard to these symptoms, because they are likely to be triggered in a variety of situations. It appears that being relatively defused from (i.e. having low levels of cognitive fusion) such thoughts is also likely to be adaptive.

It was surprising that none of the measures of cognitive appraisal were found to be significant mediators of the relationship between symptoms of MS and satisfaction with life. In the cases of ICQ- helplessness and IPQ-personal control, they became non-significant in multiple mediation analysis (when the indirect effect they shared with other mediators was taken into account), while they appeared to be significant mediators of the relationship between symptoms of MS and satisfaction with life when run alone in simple mediation analysis (see section 3.3.4.2.). It is possible that when the indirect effects associated with ACT processes are controlled for, the appraisal measures account for no significant additional specific indirect effects. ICQ- perceived benefits and IPQ- concern were not significant mediators of the relationship between symptoms of MS and satisfaction with life, even when run individually in separate simple mediation analyses.

#### **4.1.3 Comparing the roles of cognitive appraisals and ACT processes in the process of psychological adjustment to MS**

Results supported hypothesis 5, with ACT processes appearing to be stronger mediators of the relationship between MS symptoms and outcome measures. The ACT measures were the strongest mediators in both multiple mediation analyses. All statistically significant pair-wise comparisons involved one of the ACT measures demonstrating stronger specific indirect effects in comparison to a measure of cognitive appraisal. While some appraisal measures may have appeared to be significant mediators when run individually in simple mediation analyses, their specific indirect effects were non-significant when part of a multiple mediation analysis including ACT measures (with the single exception of IPQ- personal control remaining significant when the HADS was DV).

The overall finding of ACT measures being stronger mediators of the relationship between symptoms of MS and outcome measures can be related to the core debate between CBT and ACT (see section 1.4.5). This debate centres on whether it is the *content* of thought that causes psychopathology and problems in adjustment to chronic health conditions, and thus should be the target of psychological treatment (e.g. Beck *et al.*, 1979), or whether more *contextual* approaches (Hayes *et al.*, 2011) that focus on the ways individuals *relate* to their experiences may also be appropriate. The current results support ACT processes as being more significant in the process of psychological adjustment to MS, in comparison to illness related appraisals allied to more traditional CBT.

This raises the possibility that the way people relate to their thoughts and feelings regarding symptoms of MS may be a pivotal element of adjustment, rather than the *presence of* such thoughts and feelings. For example, it may be difficult for some people to avoid having thoughts about being helpless in regard to MS, having little personal control over it, or feeling concerned over its impact, but maybe such cognitions are not necessarily problematic if individuals are willing to experience them as mental events rather than ‘truths’, and are perhaps able to defuse from them,

in the service of continuing to pursue their directions for valued living. The results are consistent with this possibility.

There are, however, factors in the measurement of acceptance in the current study that could possibly bias findings slightly in favour of acceptance, as measured by the MSAQ. Firstly, it was the only measure of mediation that was MS specific, rather than referring more generally to the experience of illness. Secondly, acceptance as defined in ACT inherently involves taking action in living ones' life in valued directions. Hence, the MSAQ- engagement items refer to observable behaviour, rather than focussing on cognition and appraisal alone like other measures employed. Items which refer to engaging in valued activity are perhaps particularly likely to correlate with satisfaction with life, and reduced psychological distress. In terms of face validity, however, the items of both subscales of the MSAQ (see 6.7), do also appear to capture the more 'cognitive' element of acceptance, regarding how individuals relate to their experiences.

## **4.2 Comment on design and methodology of study**

### **4.2.1 Relative strengths of current research**

The current study was well powered, using a representative sample of individuals attending NHS services with a diagnosis of MS. The sample had a broad range of ages, time since diagnosis, a mix of individuals with different disease types (i.e. relapse/remitting or progressive), and reasonably typical ratio in terms of gender (females are more commonly affected in a ratio of 3:2). All participants were clients known to NHS neuro-rehabilitation services, which may have biased the sample slightly towards individuals experiencing some difficulties in adjusting to their condition. This possibility is supported by the somewhat elevated scores on the HADS among the sample (see section 3.2.2).

The mediator measures in the current study were chosen carefully on the basis of underlying psychological theory. The measures of appraisal were all chosen to capture cognitions which have been highlighted by previous research and reviews of the literature (e.g. Dennison *et al.*, 2009) to be relevant to adjustment outcome, while avoiding theoretical overlap with the measures of MS symptoms and adjustment outcomes. Thorough preliminary analysis was conducted to avoid collinearity between measures, test whether predictor variables correlated appropriately with DVs, and to assess whether demographic variables required inclusion as covariates.

The inclusion of numerous potential mediating variables in analysis, along with covariates where appropriate, is a definite strength of the current study. Preacher and Hayes (2008) describe how including multiple mediators in the same model reduces the risk of biased parameter estimates due to omitted variables, which can occur if single mediators are run alone in numerous simple mediation analyses (as carried out in supplemental analysis of section 3.3.4.2). Put simply, if mediators are tested alone through simple mediation analyses, they may have effects attributed to them which are more due to latent variables absent from the model. While the spread of measures and covariates included reduced the ‘omitted variable problem’ in the current study, there are perhaps some latent variables which could have been beneficial inclusions, which shall be discussed shortly.

#### **4.2.2 Weaknesses and limitations of current research**

The current research relied exclusively on self-report measures. While measures of certain constructs (e.g. cognitive appraisals, cognitive fusion, or satisfaction with life) are highly subjective and thus appropriate for self-report measure, others would have benefited from being measured more objectively by a third party to avoid biases in individuals’ perception. MS symptoms would ideally have been assessed with a clinician administered measure such as the EDSS (Kurtzke, 1983), and levels of psychological distress could similarly have been assessed through a clinical interview, such as the Structural Clinical Interview for Axis 1 disorders (First *et al.*, 1994), based on diagnostic criteria of the Diagnostic and Statistical Manual IV



(DSM-IV; American Psychiatric Association, 1994). The details participants provided regarding their condition (time since diagnosis and disease type) would also have benefited from some kind of objective verification. Such procedures were, unfortunately, not possible due to practical constraints of the research.

The absence of any measure of coping is a limitation of the current study. Coping is considered to be an important predictor of psychological outcomes by the SCM (Lazarus & Folkman, 1984) and the CSM (Leventhal *et al.*, 1984), and has been shown to be related to adjustment outcomes among PwMS (Dennison *et al.*, 2009). Adding a measure of coping to analysis would have provided a more inclusive range of variables known to be related to outcomes among people with MS. Including a fuller range of relevant psychological processes in the same analysis would have allowed a more meaningful comparison of the extent to which each mediates the relationship between MS symptoms and outcomes. The reasons for not including a measure of coping were both pragmatically and theoretically driven. Pragmatically, the inclusion of further measures would have increased the response burden for participants, and could potentially have impacted upon response rates. Therefore, only measures which were considered to be most theoretically relevant to the research aims were included. Previous research (e.g. Heijmans *et al.*, 1998, Moss-Morris *et al.*, 1996; as cited in Vaughan *et al.*, 2003) has suggested that illness representations demonstrate some direct influence on outcomes that is not mediated by coping strategies, and that they tend to be more strongly related to adjustment outcomes than coping strategies. The measurement of coping has also come under some criticism. For example, it has been argued (e.g. Coyne & Racioppo, 2000; McCracken & Eccleston, 2003) that the use of questionnaire measures which require respondents to reflect upon coping efforts in a general and somewhat abstract sense, gather no detail about the behavioural context of the coping or its subsequent success in regulating internal or external states, so yield information with relatively limited utility. Primarily, however, coping measures were not included because the current study aimed to take as exclusive a focus as possible on internal mental representations and appraisal, rather than observable coping efforts. Such a focus was considered to be suitable for directly comparing the roles of appraisals (aiming to

measure cognitive *content*), and ACT processes (aiming to capture the process of *relating to* internal experiences) in mediating the relationship between symptoms of MS and psychological adjustment.

The adoption of an exclusive focus on appraisals and ACT processes to the exclusion of coping is, however, potentially highly problematic. Coping strategies are widely believed to be important variables in the process of adjustment to MS (Dennison *et al.*, 2009). The inclusion of only a small number of psychological variables, when others are known from previous research to be potentially significant in the current context, may increase the likelihood of those variables appearing to be significant mediators. This narrowed focus somewhat limits the interpretation of results. The exclusive focus on appraisals and ACT processes may have biased the results towards confirming their significance in mediating the relationship between symptoms of MS and adjustment, while the possibility of evidence being gathered to disconfirm their significance (which could have been afforded by the inclusion of coping measures) may have been artificially limited. The items of the MSAQ do include some reference to observable behaviour. It is possible, therefore, that the MSAQ may capture some variance which could potentially have been shared with more behavioural measures of coping. It is possible that the inclusion of a coping measure could have changed the relationships among variables, or perhaps diminished the significance of ACT processes. The inclusion of coping would have provided a fuller and more comprehensive exploration of the process of adjustment to MS, which would have increased the depth of interpretation possible from the results. The omission of coping does, of course, constitute a major limitation of the current research, and very much limits the confidence with which ACT constructs can be considered to be significant mediators of the relationship between symptoms of MS and psychological adjustment.

Perhaps the most significant limitation of the current study is the absence of any measure of cognitive functioning, when cognitive impairment (including processes of concentration, memory, reasoning and judgement) is a relatively common, and potentially disabling, symptom for PwMS (Mohr & Cox, 2001). The MS-

psychological subscale was not an appropriate measure in this regard, with only one item (“Problems concentrating?”) pertained to cognitive functioning, with all other items related more directly to mood. Unfortunately, relying on self-reports of cognitive impairment among PwMS is problematic. Benedict *et al.* (2003; 2004) developed the Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ) to assist in screening for neuropsychological impairment. The MSNQ produces both self-report and informant-report scores. The authors found the informant-report version to correlate with objectively measured cognitive functioning. The self-report version, however, did not correlate with objectively measured cognitive performance, but rather correlated with symptoms of depression. Other studies have similarly found self-reports of cognitive impairment among PwMS to be confounded by depression and fatigue (DeLoire *et al.*, 2006), and that there is a lack of relationship between individuals’ perceptions of their cognitive impairments and their objectively measured cognitive functioning (Middletona, 2006). While cognitive impairment in MS can be effectively screened with brief clinician administered tests, such as the symbol digit modalities test (DeLoire *et al.*, 2006; Parmenter *et al.*, 2007), this was not feasible due to practical constraints in the current research. It is debatable whether a self-report measure such as the MSNQ would have been a wise addition to mediation analyses, because its correlation with symptoms of depression may have confounded variance more appropriately belonging to the HADS.

The measures of ACT processes, the MSAQ and the CFQ, have not previously been validated among PwMS. The MSAQ was a pilot measure, so the current study offers the only available evidence for its reliability and validity. The MSAQ total score demonstrated acceptable internal consistency in this study ( $\alpha = .87$ ). It also showed a strong negative correlation ( $r_s = -.59$ ) with the AAQ-II (Bond *et al.*, in press), a measure of psychological inflexibility, and a strong negative correlation with the CFQ ( $r = -.59$ ), providing preliminary evidence of concurrent validity. Factor analysis was not conducted with the MSAQ due to insufficient sample size, so it is unknown whether it replicates the two factor structure of the CPAQ, the measure from which it was adapted. Clearly, the MSAQ requires further validation in larger

samples of PwMS. Further research could investigate test/re-test reliability of the MSAQ, its sensitivity to detect changes in acceptance within individuals over the course of interventions, and its ability to predict later scores in adjustment outcomes (i.e. predictive validity) over the course of longitudinal research. As discussed further in section 4.3.1, it is also unclear at this stage of development to what extent the MSAQ successfully operationalizes an ACT consistent conceptualisation of acceptance, or whether it may also measure elements of acceptance as conceptualised in other models. Taken together, the limited evidence of reliability and validity for MSAQ requires that results obtained should be interpreted with caution. Therefore, this also limits the confidence with which results can be generalised to the wider population of PwMS, and the confidence with which any possible implications of the research can be stated.

While the CFQ is at a relatively advanced stage of development, having demonstrated psychometric properties such as: good internal consistency; a coherent factor structure across different samples; correlations in expected directions with related constructs; and some utility in discriminating between healthy individuals and those suffering from psychological disorders (Gillanders *et al.*, 2010); it is worth noting that data pertaining to development of the CFQ has not yet been published and subjected to peer review. The CFQ has not been validated previously for use in a MS population. In the current sample, the CFQ total score demonstrated acceptable internal consistency ( $\alpha = .85$ ), and showed a strong positive correlation ( $r_s = .74$ ) with the AAQ-II, a measure of psychological inflexibility, providing some evidence of concurrent validity. Other aspects of the validity of the CFQ in a MS population, such as its test/re-test reliability, its sensitivity to changes in cognitive fusion within individuals over time, or its ability to discriminate between PwMS suffering from psychological disorders and those who are not, are as yet unknown. Factor analysis was not conducted for CFQ in the current study, so it is unknown whether a single factor structure would be evident in this population. While Gillanders *et al.* (2010) report that the CFQ correlates with related constructs in predictable ways (see section 2.3.5), it is striking that the CFQ correlated highly ( $r = .75$ ) with psychological distress in the current study. While cognitive fusion is conceptualised as a core

process underlying psychopathology in ACT, such a high correlation does raise the possibility that the items of the CFQ could be seen as somewhat confounded with symptoms of anxiety or depression. This raises the possibility that the CFQ may not operationalize the construct of cognitive fusion in a MS population to the exclusion of other related constructs. These uncertainties surrounding the validity of the CFQ in a MS population carry the same limitations described above pertaining to the MSAQ; results regarding the CFQ must similarly be interpreted with caution. In summary, due to the uncertainty regarding the psychometric properties of the measures employed, the current results can lend only preliminary support for the possibility of ACT processes offering any new perspective on the process of psychological adjustment to MS, or for ACT interventions being potentially appropriate for PwMS.

The inclusion of the MSAQ as the sole measure of ‘acceptance’ limits the conclusions which can be drawn regarding the role of acceptance in adjustment to MS. Including only one measure of acceptance has potential to introduce some bias to the findings, because any single measure of acceptance is, perhaps, inherently quite likely to be a significant mediating variable in the context of the current study. This may render the research hypotheses - regarding acceptance as conceptualised in ACT being a significant mediator of the relationship between symptoms of MS and psychological adjustment - very likely to be confirmed. The inclusion of an alternate measure of acceptance would have increased the breadth of analysis, and the scope for evidence being gathered to disconfirm acceptance, as conceptualised in ACT, as being a significant mediating variable. Such an addition would have significantly increased the scientific rigour of the current study, by increasing the scope for research hypotheses to be falsified. The current study would have benefited from the inclusion of an alternate measure of acceptance, which was less grounded in the ACT model, so the merits of different conceptualisations of acceptance could have been directly compared. It is possible that the inclusion of an alternate measure of acceptance would have decreased the magnitude of effect sizes attributed to the MSAQ as a mediating variable, and offered a wider perspective on how ‘acceptance’ may be most usefully conceptualised in a MS population. In these regards, it would

certainly have been preferable to have issued participants with the ‘acceptance’ subscale of the ICQ, so this could have been included as a variable in mediational analyses.

The IPQ subscales employed were all single items scales. While single item scales have some obvious advantages such as being quick and easy for respondents to complete, and may be appropriate and reliable in instances when the underlying construct being measured is homogeneous (Loo, 2001), they also have some notable limitations. They may not be able to meaningfully capture more complex constructs. When complex constructs are represented by single items, this may require respondents to make personal judgements regarding what information is irrelevant to their response, and how to weigh up the relative importance of information that could influence a final score (De Boer *et al.*, 2004). This can introduce some ambiguity to interpretation of scores, as it can be unclear how respondents are interpreting the question. In the current study, for example, there could be variability in how respondents interpret the IPQ-personal control item. It could be answered in regard to their perceived control in literally influencing the disease process, feelings of control experienced in making practical adjustments in living with the condition, or how much control they experience over feelings of well-being despite experiencing symptoms of MS. The inclusion of multiple items to measure more complex latent constructs is widely believed to have various advantages. The inclusion of multiple items facilitates the calculation of internal consistency to support the validity of the measure in operationalizing the desired construct, and can increase responsiveness (Martinez-Martin, 2010). The random error of the measurement is also reduced by the inclusion of multiple items, resulting in more precise measurement (Gardner *et al.*, 1998). Given the potential complexity of the constructs measured by single scales in the current study, it is debatable whether they were optimally captured by the brief-IPQ. The use of multiple items to measure these constructs, potentially through use of the IPQ-R (Moss-Morris *et al.*, 2002), would have been likely to increase the reliability and validity of measurement of these illness representations, and would have increased the confidence with which conclusions could be drawn from the results.

The choice to include only certain subscales of the brief-IPQ in analysis may be somewhat controversial. By excluding certain subscales, Leventhal *et al.*'s (1984) model of illness representations cannot be investigated as a coherent whole. As detailed in section 2.3.3, however, omission of certain subscales appeared necessary to avoid confounding with other measures, while other representations appeared to have low face validity for a MS population when represented by single item measures. The subscales included in analysis were selected on the basis of their relevance to the process of adjustment to MS demonstrated in previous research, and their contribution to an inclusive selection of illness appraisals when considered alongside those of the ICQ. The aim of the current research was not to solely investigate Leventhal *et al.*'s (1984) CSM, but to compare the roles of relevant illness appraisals, and ACT processes, in psychological adjustment to MS. In the context of this aim, it was deemed appropriate to select only the most relevant subscales. If all subscales had been included, this could potentially have been problematic for analysis. Multiple mediation analysis (Preacher & Hayes, 2008) considers each variable's *specific indirect effect* (i.e. their unique effect beyond that shared with other variables). Therefore, as the number of variables in analysis increases, so does the amount of variance that is likely to be shared among variables. Having a greater number of appraisal measures in analysis would, therefore, be likely to decrease the chances of statistically significant mediating effects being detected. On this basis, it was considered prudent to keep the number of appraisal measures in analysis to a minimum.

The current study employed only two outcome measures. Previous studies of adjustment to MS (e.g. Jopson & Moss-Morris, 2003; McCabe *et al.*, 2004; Van Kessel *et al.*, 2008; Vaughan *et al.*, 2003) have included a wider range of outcome measures, including: QoL, sickness impact, self-esteem, work and social adjustment, fatigue severity, and engagement in activities of daily living. Wider measures of outcome were not included because: some would have been confounded with other measures (particularly the MSIS- physical), item burden would have been increased for participants and potentially have negatively impacted upon response rate, and

most importantly, an exclusive focus on subjectively experienced well-being was thought most appropriate for testing of the research hypotheses. The SWLS and HADS were thought to be appropriate choices for measuring positively and negatively valenced experiences of well-being. In focussing on subjectively experienced psychological well-being, a measure of more positive affect may have been a reasonable addition. A brief measure of social support / relational functioning could also have been a reasonable inclusion as a possible covariate.

It should be noted that in the packs issued to participants, the questionnaires always appeared in the same order. It is possible that order of the questionnaires could have had an influence on the way in which they were completed by respondents. As described by McColl *et al.* (2003), the content of initial items provides the context for subsequent items, bringing certain concepts or ideas to the front of individuals' minds, potentially impacting on the way subsequent items are interpreted and responded to. In the current study, for example, the first questionnaire was the measure of MS symptomatology (the MSIS). It is, therefore, possible that non-illness-specific measures (the CFQ, SWLS, and the HADS) could have tended to be completed with MS symptoms to some extent 'in mind'. McColl *et al.* (2003) also describe how fatigue can affect responding in a variety of ways, including respondents abandoning questionnaires, missing data (either accidentally or intentionally), or adopting habitual response patterns (e.g. choosing the same response for every item). This could introduce the possibility of data quality obtained from questionnaires presented later in the pack being slightly poorer in comparison to those presented earlier. Some researchers (e.g. Lucas, 1992) have suggested that questionnaires should be issued to respondents in a counterbalanced or randomised manner to avoid 'order effects', which would have been a wise addition to the design of the current research.

It is important to note that while the results of the current study support the hypothesis of ACT processes as mediating the relationship between symptoms of MS and psychological adjustment, causality cannot be inferred from this cross-sectional study design. The indirect effects investigated in mediational analyses are the sum of



regression coefficients, which are correlational in nature. Causality cannot be inferred from correlation alone (Field, 2009). While the direction of the relationship between the variables can be hypothesised on theoretical grounds, it is possible that constructs effect each other in unexpected ways. For example, mood and satisfaction with life could have effects on appraisals of symptoms, acceptance, or cognitive fusion. Equally, psychological well-being could be impacting, either directly or indirectly, upon disease activity and symptoms of MS (Mohr, Goodkin *et al.*, 2001; Mohr, 2002). Potential future research to explore casual chains will be discussed in section 4.4.1.

#### **4.2.3 Review of statistical analysis employed**

The method of statistical analysis in the current study was highly appropriate for the research questions addressed. As previously discussed (see section 2.5.3), the use of Preacher and Hayes's (2008) method of multiple mediation analysis was used in favour of the popular but flawed (Hayes, 2009; MacKinnon *et al.*, 2002; Shrout & Bolger, 2002) 'causal steps approach' proposed by Baron and Kenny (1986). Use of Preacher and Hayes's approach allowed exploration of the extent to which a given variable acted as mediator while controlling for the effects of other variables entered in the model, reduced the risk of 'type one' errors due to the omission of significant variables, and enabled a comparison of the 'relative magnitudes of specific indirect effects associated with all mediators' (Preacher & Hayes, 2008, p.881). The use of 'bootstrapping' to avoid assumptions of indirect effects being normally distributed is another advantage of the Preacher and Hayes method (MacKinnon & Fairchild, 2009).

Structural Equation Modelling (SEM) was considered as a potential alternate technique for data analysis. SEM allows the testing of hypothesised relationships not only among observed variables, but also latent variables that were not included in analysis (Fife-Shaw, 2000). It facilitates the exploration of complex, or 'web like', relationships among variables. In the current data set, for example, SEM techniques could have had the potential to elucidate relationships between the various predictor

variables, as opposed to simply estimating specific indirect effects of the IVs on the DVs. It is recommended, however, that SEM requires a minimum sample size of approximately 200 participants (Hoe, 2008), so such analysis would have been underpowered in the current study.

### **4.3 The Multiple Sclerosis Acceptance Questionnaire**

The results of the current study appear promising for the newly adapted MSAQ. Chronbach's  $\alpha$  values were acceptably high for both the willingness ( $\alpha = .79$ ) and activities engagement ( $\alpha = .89$ ) subscales, as well as the total score ( $\alpha = .87$ ), suggesting good internal consistency. The willingness and activities engagement subscales showed moderate correlations with each other ( $r = .33, p < .001$ ).

The MSAQ showed appropriately high correlation with the AAQ-II ( $r_s = -.59, N = 125, p < .001$ ), supporting its construct validity as a measure of acceptance. High correlation with the CFQ ( $r = -.59, p < .001$ ) is also supportive of the MSAQ's construct validity, as there is strong theoretical overlap between acceptance and cognitive fusion. In relation to measures of cognitive appraisal the MSAQ also correlated positively with IPQ- personal control ( $r = .32, p < .001$ ), and negatively with higher scores on ICQ-helplessness ( $r = -.62, p < .001$ ) and IPQ-concern ( $r = -.51, p < .001$ ). All correlations occurred in theoretically consistent directions.

As already discussed, in the current sample the MSAQ appeared to be a significant mediator of the relationship between symptoms of MS and measures of psychological adjustment. These results not only support the notion of illness specific acceptance being a significant psychological process in adjustment to MS, but also give preliminary support for the MSAQ being an appropriate measure of that process.

The positive findings regarding the MSAQ appear to support the decision to base this MS specific measure of acceptance on the items of the CPAQ. Of course, it cannot be discerned from the current analysis whether the two subscale structure of the

CPAQ transfers to the MSAQ. Further research will require the use of factor analysis to discern the factor structure of the MSAQ, and how acceptance is best conceptualised and measured in a MS population. Factor analysis and further scale development will require the use of larger samples.

#### **4.3.1 Potential Limitations of the MSAQ**

It is important to note that the MSAQ is a measure of acceptance as conceptualised in ACT, which is quite distinct from acceptance as defined in other models discussed in adjustment literature. In research conducted by Dembo *et al.* (1956; as cited in Li & Moore, 1998) acceptance was conceptualised as an adjustment to loss, which included recognising and deemphasising values which were in conflict with disability, resisting extending the concept of impairment to wider aspects of ‘the self’, and avoiding comparisons to others in areas affected by disability. More recent research has viewed acceptance of chronic health conditions as the end ‘phase’ of a potentially long process of adjustment. Antonak and Livneh (1995), for example, describe how the process of adjusting to disability can typically involve individuals passing through the following phases: ‘shock’, ‘anxiety’, ‘denial’, ‘depression’, ‘internalised anger’ (directed towards the self), ‘externalised hostility’ (directed towards others), ‘acknowledgement’, and finally ‘adjustment’. Antonak and Levneh (1995) describe ‘acknowledgement’, the penultimate phase, as ‘intellectual acceptance’ of the implications of disability, and their incorporation into the self-concept. The final stage, ‘adjustment’, is defined as ‘emotional acceptance’, when the implications of disability are affectively internalised into the self-concept and behavioural and social adaptations are made to facilitate living with disability. In this model, which is perhaps consistent with the conception of most health professionals, the word ‘acceptance’ is almost synonymous with ‘adjustment’, marking the end phase in a long and potentially difficult process of cognitive, behavioural, and emotional adaptation. Acceptance has also been discussed as the opposite to ‘denial’ (Eccles *et al.*, 2011; Telford *et al.*, 2006), as denial is an earlier stage in the adjustment process when the individual cannot face the implications of disability. Other measures of acceptance, such as the Acceptance of Chronic Health Conditions

Scale (ACHCS; Stuifbergen *et al.*, 2008), discussed further below, have been developed with acceptance conceptualised more as an end phase in an adjustment process.

The conceptualisation of acceptance captured by the MSAQ is based on that of the CPAQ (McCracken *et al.*, 2004) from which it was adapted, viewing acceptance of MS as a willingness to experience difficult thoughts, feelings, and symptoms relating to MS in the course of engaging in personally valued activity, without attempting to control or avoid unwanted experiences. From the perspective of other models of adjustment, such as ‘phase’ models described by Antonak and Levneh (1995), this could appear a somewhat narrow definition of ‘acceptance’. For example, it could be possible for an individual to frequently experience distressing cognitions relating to their condition, with accompanying feelings of anger, injustice, and low mood, but if they carried on engaging in valued activity successfully without attempting to control these experiences, they could be viewed as exhibiting high levels of ‘acceptance’ according to an ACT model. Non-ACT practitioners could reasonably argue that such an individual may not have cognitively or emotionally ‘accepted’ the implications of their condition. Thus, the MSAQ may have little relation to acceptance as conceptualised in other models, as discussed by other professionals, and as commonly understood in lay conceptions. A willingness to experience unwanted symptoms, thoughts and feelings in the course of engaging in valued activity may have limited relation to an individual’s emotional and cognitive adjustment to the condition. It is unclear how these two conceptualisations (i.e. acceptance as defined by ACT, or acceptance as an end ‘phase’ of adjustment) may relate to, or overlap with, each other. It may be that individuals who could be described as being at the ‘end phase’ of an adjustment process are the same individuals who would appear as ‘accepting’ from an ACT standpoint, and that the MSAQ may inadvertently be measuring this underlying construct. Alternatively, it may be possible to have some dissociation between the two states, as in the hypothetical case example above.

From the current study it cannot be discerned to what extent the MSAQ exclusively captures acceptance as conceptualised by ACT, or whether it captures variance more appropriately attributable to individuals being at the later phases of an adjustment process, when their appraisals of their condition may have evolved in more adaptive directions. Of course, the items of the MSAQ could be viewed as measuring such ‘appraisals’ to some extent. This distinction between acceptance conceptualisations is also made difficult by the MSAQ’s reference to engagement in valued behaviour. Observable value driven behaviour is an inherent element of acceptance as conceptualised in ACT so was a necessary element of the measure. Engagement in valued activity is also conceptualised, however, as indicative of individuals being at a later stage in an adjustment process by ‘phase’ models (e.g. Antonak & Levneh, 1995).

It is worth noting that conceptualising acceptance as an end ‘phase’ in an adjustment process may have some disadvantages. For some individuals, more ‘phase’ based conceptualisations of acceptance (Antonak & Levneh, 1995) may carry an implication that they need to have worked through an emotional adjustment process (so they ‘feel better’) before engagement in more behaviour consistent with valued living is possible, which could have the potential to hold back progress in rehabilitation. The MSAQ aims to measure an essentially behavioural conceptualisation of acceptance, whereby individuals are considered to be capable of engaging in ‘acceptance’ consistent behaviour while still experiencing unwanted mental events. Some individuals could experience such an ACT consistent conceptualisation of acceptance as being quite liberating. The MSAQ hopefully captures an ACT conceptualisation of acceptance more explicitly and effectively compared to other existing measures.

One potentially interesting area of research would be to include the MSAQ in research alongside other existing measures of ‘acceptance’ of chronic illness. The ACHCS (Stuifbergen *et al.*, 2008), for example, was developed to move away from previous definitions of acceptance as a process of adjustment to loss (Linkowski, 1971), to one linked to more adaptive processes (see earlier quotations in section

1.3.2.2). Stuijbergen *et al.* (2008) cite a range of previous research as influencing the development of their scale, including work by ACT researchers in chronic pain (e.g. McCracken & Vowles, 2006) and that of more ‘phase’ based models (e.g. Antonak & Levneh, 1995). Their definitions of acceptance clearly differ from that of ACT, as do some items of the scale (e.g. ‘I’ve come to terms with my MS’, ‘I think of MS as just part of who I am’). The definition of acceptance employed by Stuijbergen *et al.* (2008) is based more on ‘phase’ based conceptions of adjustment which inherently involve change in cognitive content. The Ideas About Long-Standing Health Problems (IALHP) questionnaire developed by McDonald *et al.* (2011) is another measure of acceptance for individuals with chronic health problems. The IALHP appears to be based on theoretically diverse, and perhaps somewhat confused, definitions of acceptance, including: ‘Acceptance of chronic illness is conceptualized as the desire to take possession of one’s illness’ (p.416). The IALHP has three subscales measuring: outlook, confidence, and presence of inhibitors. Inspection of items suggests it has very little theoretical overlap with acceptance as defined in ACT, and again relates more to cognitive content. Comparison of the MSAQ with other measures of ‘acceptance’ of chronic health conditions, perhaps in analysis similar to that employed in the current study, could elucidate whether a more appraisal based (e.g. Stuijbergen *et al.*, 2008) measure of acceptance could account for any variance in outcome beyond the more ACT consistent MSAQ, or whether the variance captured by the MSAQ is more appropriately conceptualised by alternative models of acceptance.

It is perhaps important that researchers remain aware of the differences between an ACT conceptualisation of acceptance, and those of other models (e.g. Antonak & Levneh, 1995; Stuijbergen *et al.*, 2008). It is striking that that some authors discussing acceptance in the context of questionnaire development (e.g. Evers *et al.*, 2001; McDonald *et al.*, 2011; Stuijbergen *et al.*, 2008) appear to move between definitions: for example describing acceptance the end phase of an adjustment process, before citing ACT studies as demonstrating the importance of this process for psychological outcome. In this context, it may be somewhat unfortunate that

ACT uses the term ‘acceptance’ (as opposed to alternatives such as ‘willingness’) when this risks causing conceptual confusion.

## **4.4 Implications and potential future research**

### **4.4.1 Potential future research**

The results of the current research suggest that the relevance of ACT processes in adjustment to MS are worthy of further investigation.

As already discussed (see section 4.2.2.), the direction of causality among the variables measured cannot be discerned from the current research. More sophisticated designs are necessary to evidence causality of any mediational effect, including longitudinal design to show whether scores in proposed mediators at ‘time 1’ predict scores in outcomes at ‘time 2’. The inclusion of process measures in intervention research is particularly useful in these regards, with process measures (e.g. of ACT processes, or cognitive appraisals) being completed at baseline, mid-treatment, and post-intervention (Kraemer *et al.*, 2002). Daily process studies (e.g. Tennen *et al.*, 2000) could be fruitful in exploring the purported mechanisms of ACT, or indeed CBT, interventions in a MS population, potentially involving monitoring of fluctuations in: MS symptoms, cognitive processes (i.e. willingness, cognitive defusion, cognitive appraisals, mindfulness), mood, and engagement in values congruent activity. Experimental designs also have useful potential in gathering evidence for hypothesised causal chains (MacKinnon & Fairchild, 2009; Spencer *et al.*, 2005).

Of course, future studies of ACT interventions (delivered to individuals or groups) in a MS population would have the primary aim of investigating the efficacy of treatment. To date, only one very preliminary study has investigated the effectiveness of an ACT intervention in a MS population (Sheppard *et al.*, 2010), and another one (Grossman *et al.*, 2010) has investigated the impact of mindfulness training (see section 1.5.6.2.6 for details). The authors of these two studies both commented, in reference to ACT and mindfulness respectively, how such interventions could



potentially be highly appropriate for a MS population, given their broad focuses, and the notion that such interventions do not seek to change or challenge cognitive content (which may not be realistic or possible when faced with certain cognitions and challenges relating to MS). The results of the current study support the possible applicability of ACT, or indeed mindfulness, interventions in a MS population. In line with recommendations made by previous reviews of the ACT evidence base (e.g. Ost, 2008; Powers *et al.*, 2009), studies of ACT interventions in MS populations should aim to employ as rigorous methodologies possible, including: representative samples, random assignment to treatments, inclusion of waiting list and/or psychological placebo control groups, comparison with a treatment of proven efficacy (such as CBT), use of reliable and valid outcome measures, reasonable numbers of therapists involved in trials (to avoid therapist effects) with good levels of experience, monitoring of treatment adherence, and control of concomitant treatments (Ost, 2009).

Carefully conducted intervention research could potentially inform clinicians' tailoring of interventions for given individuals. It could be possible, for example, that ACT and CBT interventions could be differentially effective for different presenting problems, or for individuals experiencing different types of the disease (i.e. relapse/remitting or progressive). It seems feasible that skills learnt from ACT interventions may be useful both for individuals who are relatively newly diagnosed, and those who are experiencing more marked disability. Another important question is how effective ACT and CBT interventions may be for individuals experiencing differing levels of cognitive impairment.

As previously discussed (see section 4.3), further research could also aim to explore the reliability and validity of the MSAQ, conducting factor analysis to determine whether it replicates the two-factor structure of the CPAQ. The MSAQ could also be compared to other measures of 'acceptance' in chronic health conditions, such as the ACHCS developed by Stuijbergen *et al.* (2008), to explore the relative merits of different conceptualisations of acceptance.

#### **4.4.2 Possible implications**

While the results of the current study give only very preliminary support for the relevance of ACT processes to psychological adjustment in a MS population, they raise interesting questions about how ACT interventions would potentially impact upon the care of PwMS in light of relevant policy documents (if further research provided support for its relevance and utility).

The National Institute of Health and Clinical Excellence (NICE) has produced guidelines for the management of multiple sclerosis in primary and secondary care (NICE, 2003), recommending that specialist neurological rehabilitation services should have a clinical psychologist as an integral member of the team. The guidelines state that PwMS who are experiencing significant symptoms of depression should be offered CBT ‘as part of an overall programme of depression management’ (p.37), and that psychologically based treatments should also be offered to individuals suffering from anxiety. These are obviously roles in which clinical psychology would be expected to take a lead, and in which ACT interventions are worthy of further exploration.

It is also interesting to consider, however, how the practice of ACT could potentially impact upon a wider team approach. The NICE (2003) guidelines put emphasis on the multi-disciplinary team (MDT) working in collaboration with the client (and their family) to establish agreed goals to work towards with ‘an agreed common therapeutic approach’ (p.9). Clinical psychologists’ skill mix puts them in strong position to play an instrumental role in helping the MDT reach a formulation of clients’ problems that can inform a coordinated team intervention. ACT could perhaps be an appropriate framework on which to base such a team approach. ACT’s emphasis on exploring individuals’ directions for valued living, identifying unworkable action currently being taken (including evidence of experiential avoidance and cognitive fusion), before encouraging committed action in valued directions (Harris, 2009) appears quite compatible with the kind of approach a specialist neurological rehabilitation service may take in identifying and working

towards goals with clients. The relative simplicity of ACT formulations, and its ultimately behavioural emphasis, may make it a readily accessible common framework for MDT members to work with.

An ACT informed approach to rehabilitation could impact upon how all MDT members understand clients' experiences, and how they respond to clients in direct work. Within an ACT framework, there would perhaps be an increased appreciation among professionals that certain difficult thoughts and feelings that clients experience regarding MS are, to some extent, unavoidable. In some instances, attempts to challenge, discourage, avoid, or suppress these experiences may be unrealistic and counterproductive. Clinical Psychologists could potentially play a role in training other professionals to employ ACT based skills (i.e. acceptance and cognitive defusion exercises) with their clients to help them *relate* to their difficult experiences in new ways, to facilitate increased engagement in valued living.

Both the NICE (2003) guidelines for MS and The National Service Framework for Long-Term Conditions (Department of Health, 2005) emphasise that the MDT team should provide support to the family and carers of PwMS. Again, ACT may provide an appropriate framework for supporting family members and carers to cope with stress related to caring for individuals with MS. Brief acceptance and mindfulness based interventions have previously been piloted among support staff caring for individuals with learning disabilities (Noone & Hastings, 2009; Noone & Hastings, 2010), and were found to reduce levels of psychological distress.

Of course, all the possible applications of ACT in the care of PwMS discussed here are highly speculative, given that this study offers only the most preliminary evidence of the relevance of ACT processes in this population. It is not the intention on the current discussion to 'get ahead of the data'. It is, however, worthwhile to note the diverse areas of potential applicability for ACT in a MS population, which may be worthy of further consideration and research in the context of existing policy for the provision of care.

## 4.5 Summary and Conclusions

The current study aimed to investigate the roles of ACT processes (acceptance and cognitive fusion) and cognitive appraisals in mediating the relationship between symptoms of MS and adjustment outcomes (satisfaction with life, and psychological distress).

Through multiple mediation analyses (Preacher and Hayes, 2008), there was surprisingly limited evidence for cognitive appraisals acting as significant mediators, with only appraisals relating to personal control over one's illness mediating the relationship between symptoms of MS and psychological distress. The measures of ACT processes, however, showed evidence of being stronger mediators of the relationships between symptoms of MS and both outcome measures. The newly adapted MSAQ appeared to perform well as a measure of MS specific 'acceptance'. Further research may seek to explore the reliability and validity of the MSAQ in a larger population.

The current results are consistent with the ACT constructs of 'acceptance' and 'cognitive fusion' being significant psychological processes in adjustment to MS, mediating the relationship between physical symptoms of MS and psychological outcome measures. The results raise the possibility that the way people *relate* to their thoughts and feelings regarding symptoms of MS may be a pivotal element of adjustment, rather than the mere *presence of* such thoughts and feelings. The results support suggestions by other authors (Dennison & Moss-Morris, 2010; Grossman *et al.*, 2010; Sheppard *et al.*, 2010) that more 'third wave' or 'contextual' approaches (Hayes *et al.*, 2011) such as ACT may be appropriate interventions in a MS population given their broad focuses, and the notion that such interventions do not seek to change or challenge cognitive content (which may not be realistic or possible when faced with certain cognitions and challenges relating to MS).

The cross sectional design of the current research makes it impossible to reach any conclusions about the direction of causality among variables, but these preliminary

results suggest that the relevance of ACT processes, and perhaps ACT interventions, may be worthy of further investigation in a MS population.

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## 6 Appendices

### Multiple Sclerosis Impact Scale (MSIS-29)

- The following questions ask for your views about the impact of MS on your day-to-day life **during the past two weeks**
- For each statement, please **circle** the **one** number that **best** describes your situation
- Please answer **all** questions

| In the <b>past two weeks</b> , how much has your MS limited your ability to... |   | Not at all | A little | Moderately | Quite a bit | Extremely |
|--|---|------------|----------|------------|-------------|-----------|
| 1.   | Do physically demanding tasks?              | 1          | 2        | 3          | 4           | 5         |
| 2.   | Grip things tightly (e.g. turning on taps)? | 1          | 2        | 3          | 4           | 5         |
| 3.   | Carry things?                               | 1          | 2        | 3          | 4           | 5         |

| In the <b>past two weeks</b> , how much have you been bothered by... |  | Not at all | A little | Moderately | Quite a bit | Extremely |
|--|--|------------|----------|------------|-------------|-----------|
| 4.   | Problems with your balance?                      | 1          | 2        | 3          | 4           | 5         |
| 5.   | Difficulties moving about indoors?               | 1          | 2        | 3          | 4           | 5         |
| 6.   | Being clumsy?                                    | 1          | 2        | 3          | 4           | 5         |
| 7.   | Stiffness?                                       | 1          | 2        | 3          | 4           | 5         |
| 8.   | Heavy arms and/or legs?                          | 1          | 2        | 3          | 4           | 5         |
| 9.   | Tremor of your arms or legs?                     | 1          | 2        | 3          | 4           | 5         |
| 10.  | Spasms in your limbs?                            | 1          | 2        | 3          | 4           | 5         |
| 11.  | Your body not doing what you want it to do?      | 1          | 2        | 3          | 4           | 5         |
| 12.  | Having to depend on others to do things for you? | 1          | 2        | 3          | 4           | 5         |

Please check that you have answered all the questions before going on to the next page  
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 Queen Square, London WC1N 3BG, UK

| In the past two weeks, how much have you been bothered by...  |  | Not at all | A little | Moderately | Quite a bit | Extremely |
|---|--|------------|----------|------------|-------------|-----------|
| 13.   | Limitations in your social and leisure activities at home?                         | 1          | 2        | 3          | 4           | 5         |
| 14.   | Being stuck at home more than you would like to be?                                | 1          | 2        | 3          | 4           | 5         |
| 15.   | Difficulties using your hands in everyday tasks?                                   | 1          | 2        | 3          | 4           | 5         |
| 16.   | Having to cut down the amount of time you spent on work or other daily activities? | 1          | 2        | 3          | 4           | 5         |
| 17.   | Problems using transport (e.g. car, bus, train, taxi, etc.)?                       | 1          | 2        | 3          | 4           | 5         |
| 18.   | Taking longer to do things?  | 1          | 2        | 3          | 4           | 5         |
| 19.   | Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?  | 1          | 2        | 3          | 4           | 5         |
| 20.   | Needing to go to the toilet urgently?  | 1          | 2        | 3          | 4           | 5         |
| 21.   | Feeling unwell?  | 1          | 2        | 3          | 4           | 5         |
| 22.   | Problems sleeping?   | 1          | 2        | 3          | 4           | 5         |
| 23.   | Feeling mentally fatigued?   | 1          | 2        | 3          | 4           | 5         |
| 24.   | Worries related to your MS?  | 1          | 2        | 3          | 4           | 5         |
| 25.   | Feeling anxious or tense?  | 1          | 2        | 3          | 4           | 5         |
| 26.   | Feeling irritable, impatient, or short tempered?                                   | 1          | 2        | 3          | 4           | 5         |
| 27.   | Problems concentrating?  | 1          | 2        | 3          | 4           | 5         |
| 28.   | Lack of confidence?  | 1          | 2        | 3          | 4           | 5         |
| 29.   | Feeling depressed?   | 1          | 2        | 3          | 4           | 5         |
| Please check that you have circled ONE number for EACH question   |  |            |          |            |             |           |
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### Illness Cognition Questionnaire

On this page is a list of statements from people with long-term illnesses. Please indicate the extent to which you agree with these statements by circling one of the answers following the statement. An example is given below.

If you agreed with the statement, **to a large extent**, you would circle 3 (as shown):

|  | not<br>at all | somewhat | to a<br>large<br>extent | completely |
|--|---------------|----------|-------------------------|------------|
| Because of my illness I miss the things I like to do most. | 1             | 2        | 3                       | 4          |

Do not spend too much time considering your answers. Your first impression is usually the best

**To what extent do you agree with the following statements?**

|   | not<br>at all | somewhat | to a<br>large<br>extent | completely |
|---|---------------|----------|-------------------------|------------|
| 1. Because of my illness I miss the things I like to do most.                                       | 1             | 2        | 3                       | 4          |
| 2. Dealing with my illness has made me a stronger person.   | 1             | 2        | 3                       | 4          |
| 3. My illness controls my life.   | 1             | 2        | 3                       | 4          |
| 4. I have learned a great deal from my illness.   | 1             | 2        | 3                       | 4          |
| 5. My illness makes me feel useless at times.   | 1             | 2        | 3                       | 4          |
| 6. My illness has made life more precious to me.  | 1             | 2        | 3                       | 4          |
| 7. My illness prevents me doing what I would really like to do.                                     | 1             | 2        | 3                       | 4          |
| 8. Looking back, I can see that my illness has also brought about some positive changes in my life. | 1             | 2        | 3                       | 4          |
| 9. My illness limits me in everything that is important to me.                                      | 1             | 2        | 3                       | 4          |
| 10. My illness frequently makes me feel helpless.   | 1             | 2        | 3                       | 4          |
| 11. My illness has helped me realise what's important in life.                                      | 1             | 2        | 3                       | 4          |
| 12. My illness has taught me to enjoy the moment more.  | 1             | 2        | 3                       | 4          |

## The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

|  |   |   |   |   |   |   |   |   |   |    |                                |
|--|---|---|---|---|---|---|---|---|---|----|--------------------------------|
| How much does your illness affect your life?   |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| no effect at all   |   |   |   |   |   |   |   |   |   |    | severely effects my life       |
| How long do you think your illness will continue?  |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| a very short time  |   |   |   |   |   |   |   |   |   |    | forever                        |
| How much control do you feel you have over your illness?   |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| absolutely no control  |   |   |   |   |   |   |   |   |   |    | an extreme amount of control   |
| How much do you think your treatment can help your illness?  |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| not at all   |   |   |   |   |   |   |   |   |   |    | extremely helpful              |
| How much do you experience symptoms from your illness?   |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| no symptoms at all   |   |   |   |   |   |   |   |   |   |    | many severe symptoms           |
| How concerned are you about your illness?  |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| not at all concerned   |   |   |   |   |   |   |   |   |   |    | extremely concerned            |
| How well do you feel you understand your illness?  |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| Don't understand at all  |   |   |   |   |   |   |   |   |   |    | understand very clearly        |
| How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed) |   |   |   |   |   |   |   |   |   |    |                                |
| 0  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |                                |
| Not at all effected emotionally  |   |   |   |   |   |   |   |   |   |    | extremely effected emotionally |

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:

1. \_\_\_\_\_
2. \_\_\_\_\_



### The Acceptance and Action Questionnaire (AAQ-II)

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

| 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|
| Never true | Very seldom true | Seldom true | Sometimes true | Frequently true | Almost always true | Always true |

|  | Never true | Very seldom true | Seldom true | Sometimes true | Frequently true | Almost always true | Always true |
|--|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|
| 1. It's OK if I remember something unpleasant.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 2. My painful experiences and memories make it difficult for me to live a life that I would value. | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 3. I'm afraid of my feelings.  | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 4. I worry about not being able to control my worries and feelings.                                | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 5. My painful memories prevent me from having a fulfilling life.                                   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 6. I am in control of my life.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 7. Emotions cause problems in my life.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 8. It seems like most people are handling their lives better than I am.                            | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 9. Worries get in the way of my success.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 10. My thoughts and feelings do not get in the way of how I want to live my life.                  | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |

### The Cognitive Fusion Questionnaire (CFQ-15)

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

| 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|
| Never true | Very seldom true | Seldom true | Sometimes true | frequently true | Almost always true | Always true |

|   | Never true | Very seldom true | Seldom true | Sometimes true | Frequently true | Almost always true | Always true |
|---|------------|------------------|-------------|----------------|-----------------|--------------------|-------------|
| 1. My thoughts cause me distress or emotional pain.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 2. I get so caught up in my thoughts that I am unable to do the things that I most want to do.              | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 3. Even when I am having distressing thoughts, I know that they may become less distressing eventually.     | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 4. I over-analyse situation to the point where it's unhelpful to me.  | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 5. I struggle with my thoughts.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 6. Even when I'm having upsetting thoughts, I can see that those thoughts may not be literally true.        | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 7. I get upset with myself for having certain thoughts.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 8. I need to control the thoughts that come into my head.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 9. I find it easy to view my thoughts from a different perspective.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 10. I tend to get very entangled in my thoughts.  | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 11. I tend to react very strongly to my thoughts.   | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 12. It's possible for me to have negative thoughts about myself and still know that I am an OK person.      | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 13. It's such a struggle to let go of upsetting thoughts even when I know that letting go would be helpful. | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 14. I can do difficult things even if my thoughts say they are impossible to do.                            | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |
| 15. I can be aware of my thoughts without necessarily reacting to them.                                     | 1          | 2                | 3           | 4              | 5               | 6                  | 7           |

**The original items of the Chronic Pain Acceptance Scale, and the corresponding adapted items of the MSAQ**

| <b>Item Number</b> | <b>Original Item from Chronic Pain Acceptance Questionnaire (CPAQ)</b>                       | <b>Adapted version of item for the Multiple Sclerosis Acceptance Questionnaire (MSAQ)</b>   |
|--------------------|--|---|
| <b>1</b>           | I am getting on with the business of living no matter what my level of pain is               | I am getting on with the business of living no matter what my symptoms of MS are.           |
| <b>2</b>           | My life is going well, even though I have chronic pain                                       | My life is going well, even though I have MS.   |
| <b>3</b>           | It's OK to experience pain   | Its OK to experience symptoms of MS.  |
| <b>4</b>           | I would gladly sacrifice important things in my life to control this pain better             | I would gladly sacrifice important things in my life to control the symptoms of MS better.  |
| <b>5</b>           | It's not necessary for me to control my pain in order to handle my life well                 | It's not necessary for me to control my symptoms of MS in order to handle my life well.     |
| <b>6</b>           | Although things have changed, I am living a normal life despite my chronic pain              | Although things have changed, I am living a normal life despite MS.                         |
| <b>7</b>           | I need to concentrate on getting rid of my pain  | I need to concentrate on doing all I can to reduce the symptoms of MS.                      |
| <b>8</b>           | There are many activities I do when I feel pain  | There are many activities I do when I experience symptoms of MS.                            |
| <b>9</b>           | I lead a full life even though I have chronic pain   | I lead a full life even though I have MS.   |
| <b>10</b>          | Controlling pain is less important than any other goals in my life                           | Controlling symptoms of MS is less important than other goals in my life.                   |
| <b>11</b>          | My thoughts and feelings about pain must change before I can take important steps in my life | My thoughts and feelings about MS must change before I can take important steps in my life. |
| <b>12</b>          | Despite the pain, I am now sticking to a certain course in my life                           | Despite MS, I am now sticking to a certain course in my life.                               |
| <b>13</b>          | Keeping my pain level under control takes first priority whenever I'm doing something        | Keeping my symptoms of MS under control takes first priority whenever I'm doing something.  |

|    |  |   |
|----|--|---|
| 14 | Before I can make any serious plans, I have to get some control over my pain             | Before I can make any serious plans, I have to get some control over my symptoms of MS.                 |
| 15 | When my pain increases, I can still take care of my responsibilities                     | When my symptoms of MS increase or relapse, I can still try my best to do the things I most care about. |
| 16 | I will have better control over my life if I can control my negative thoughts about pain | I will have better control over my life if I can control my negative thoughts about MS                  |
| 17 | I avoid putting myself in situations where my pain might increase                        | I avoid putting myself in situations where my symptoms of MS might increase.                            |
| 18 | My worries and fears about what pain will do to me are true                              | My worries and fears about my MS in the future stop me from living a fulfilling life now.               |
| 19 | It's a relief to realize that I don't have to change my pain to get on with my life      | It's a relief to realise that my symptoms of MS don't have to change for me to get on with my life.     |
| 20 | I have to struggle to do things when I have pain   | I have to struggle to do things when I experience symptoms of MS.                                       |

**Instructions for scoring the MSAQ (same as for the CPAQ):**

**Activities engagement:** compute sum of items 1,2,3,5,6,8,9,10,12,15,19.

**Willingness:** compute sum of reverse scores of 4,7,11,13,14,16,17,18,20.

**Total score** = activities engagement + willingness

### The Multiple Sclerosis Acceptance Questionnaire (MSAQ)

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

| 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
|------------|------------------|-------------|----------------|------------|--------------------|-------------|
| Never true | Very rarely true | Seldom true | Sometimes true | Often true | Almost always true | Always true |

|   | Never true | Very rarely true | Seldom true | Sometimes true | Often true | Almost always true | Always true |
|---|------------|------------------|-------------|----------------|------------|--------------------|-------------|
| 1. I am getting on with the business of living no matter what my symptoms of MS are.            | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 2. My life is going well, even though I have MS.  | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 3. Its OK to experience symptoms of MS.   | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 4. I would gladly sacrifice important things in my life to control the symptoms of MS better.   | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 5. It's not necessary for me to control my symptoms of MS in order to handle my life well.      | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 6. Although things have changed, I am living a normal life despite MS.                          | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 7. I need to concentrate on doing all I can to reduce the symptoms of MS.                       | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 8. There are many activities I do when I experience symptoms of MS.                             | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 9. I lead a full life even though I have MS.  | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 10. Controlling symptoms of MS is less important than other goals in my life.                   | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 11. My thoughts and feelings about MS must change before I can take important steps in my life. | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 12. Despite MS, I am now sticking to a certain course in my life.                               | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |



|   | Never true | Very rarely true | Seldom true | Sometimes true | Often true | Almost always true | Always true |
|---|------------|------------------|-------------|----------------|------------|--------------------|-------------|
| 13. Keeping my symptoms of MS under control takes first priority whenever I'm doing something.              | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 14. Before I can make any serious plans, I have to get some control over my symptoms of MS.                 | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 15. When my symptoms of MS increase or relapse, I can still try my best to do the things I most care about. | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 16. I will have better control over my life if I can control my negative thoughts about MS.                 | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 17. I avoid putting myself in situations where my symptoms of MS might increase.                            | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 18. My worries and fears about my MS in the future stop me from living a fulfilling life now.               | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 19. It's a relief to realise that my symptoms of MS don't have to change for me to get on with my life.     | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |
| 20. I have to struggle to do things when I experience symptoms of MS.                                       | 1          | 2                | 3           | 4              | 5          | 6                  | 7           |

## **Hospital Anxiety and Depression Scale (HADS)**

**Participants completed the official copyrighted version of the HADS. The items of the scale are simply listed here (with whether they relate to symptoms of anxiety or depression in brackets). Each item is responded to on a four point scale, with respondents rating the extent to which the item applies to them.**

I feel tense or 'wound up' (Anxiety)

I still enjoy the things I used to enjoy (Depression)

I get a sort of frightened feeling as if something awful is about to happen (Anxiety)

I can laugh and see the funny side of things (Depression)

Worrying thoughts go through my mind (Anxiety)

I feel cheerful (Depression)

I can sit at ease and feel relaxed (Anxiety)

I feel as if I am slowed down (Depression)

I get a sort of frightened feeling like 'butterflies' in the stomach (Anxiety)

I have lost interest in my appearance (Depression)

I feel restless as I have to be on the move (Anxiety)

I look forward with enjoyment to things (Depression)

I get sudden feelings of panic (Anxiety)

I can enjoy a good book or radio or TV program (Depression)

## **The Satisfaction With Life Scale**

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by circling the appropriate number on the scale alongside. Please be open and honest in your responding. The 7-point scale is as follows:

| 1                        | 2               | 3                        | 4                                 | 5                     | 6            | 7                     |
|--------------------------|-----------------|--------------------------|-----------------------------------|-----------------------|--------------|-----------------------|
| <b>strongly disagree</b> | <b>disagree</b> | <b>slightly disagree</b> | <b>neither agree nor disagree</b> | <b>slightly agree</b> | <b>Agree</b> | <b>strongly agree</b> |

|   | Strongly disagree | Disagree | Slightly Disagree | Neither agree nor disagree | Slightly agree | Agree | Strongly |
|---|-------------------|----------|-------------------|----------------------------|----------------|-------|----------|
| 1. In most ways my life is close to my ideal.                   | 1                 | 2        | 3                 | 4                          | 5              | 6     | 7        |
| 2. The conditions of my life are excellent.                     | 1                 | 2        | 3                 | 4                          | 5              | 6     | 7        |
| 3. I am satisfied with my life.                                 | 1                 | 2        | 3                 | 4                          | 5              | 6     | 7        |
| 4. So far I have gotten the important things I want from life.  | 1                 | 2        | 3                 | 4                          | 5              | 6     | 7        |
| 5. If I could live my life over, I would change almost nothing. | 1                 | 2        | 3                 | 4                          | 5              | 6     | 7        |



## **Demographic Data**

I would be grateful if you would begin by answering the questions below:

**Please state your age:** \_\_\_\_\_

**Gender:**                      Male / Female  
(please circle)

**Approximately how many years is it since you were diagnosed with MS?** \_\_\_\_\_

**Approximately how many years is it since you first experienced symptoms of MS?** \_\_\_\_\_

**Relational status:**    Married or co-habiting  
(Please circle)  
                                 Separated or divorced  
                                 Single  
                                 Widowed

**Stage of MS:**                      relapsing                      **or**                      secondary  
(please circle                      & remitting    progressive  
if known)

Clinical Psychology Department  
Sir George Sharp Unit  
Cameron Hospital  
Windygates  
KY8 5RR  
Tel: 01592 226808



**Private and Confidential**

(Insert name & address of potential  
participant if sheet is being posted)

Date: 27 July 2011  
Your Ref:  
Our Ref: CF  
Enquiries to: Clive Ferenbach  
Email: cliveferenbach@nhs.net

Dear *Insert name of potential participant*,

**Invitation to Participate in a Research Project Investigating the Process of Adjustment to  
Multiple Sclerosis**

***Invitation***

You have been identified by *Insert name and job title of relevant clinician* as someone who would potentially be suitable to participate in research I am conducting as part of a Doctoral Thesis with the University of Edinburgh. The following NHS services will be involved: the Fife Rehabilitation Service at Cameron Hospital, the Division of Clinical Neurology at the Western General Hospital, the New Royal Infirmary, the Astley Ainslie Hospital, and the Community Rehabilitation and Brain Injury Service in Livingston. This information sheet is designed to tell you about the research, so you can decide whether or not you wish to take part.

***Why are we doing this study?***

This research aims to investigate how people psychologically adjust to a diagnosis of Multiple Sclerosis (MS). Research suggests the way individuals *think* about their illness can have a significant bearing on their psychological well being. I hope to investigate what kinds of thinking are most important in helping people adjust to MS, and continue living a satisfying life.

This knowledge may help us develop more effective ways of helping people adjust to their diagnosis. It is for this reason that the NHS service you attend has chosen to collaborate on this project.

***Why have I been chosen?***

We are interested in learning more about your experiences of adjusting to MS, as someone with a diagnosis of MS, who would potentially be able to understand and complete some questionnaires.

***Do I have to take part?***

No. You are under no obligation to complete the questionnaires; your participation is entirely voluntary. If you do not choose to participate, this decision will not affect your care in any way.

---

## Second page of participant information sheet:

### *What will happen to me if I choose to take part in this research?*

You will be asked to complete eight questionnaires, which may take you about 45 minutes. These questionnaires aim to measure three things: symptoms of MS; thinking styles; and feelings of well-being (mood, and satisfaction with life). You will find these questionnaires enclosed. You will be asked to give us some details about your personal circumstances, such as your age, living situation, and approximate time since your diagnosis. We will not be able to identify you from your responses.

*If you would like to participate, you would simply have to complete the consent form, and all the questionnaires, and post them back to me with the pre-paid envelope provided.*

### *Would my information be kept confidential?*

When replies are received, we will know your name from the consent form. Provided your scores do not suggest you might be suffering significant anxiety or depression, the consent form will then be stored separately so all your information will be anonymised. If your scores on the Hospital Anxiety and Depression Scale suggest you may be suffering severe anxiety or depression, a Doctor known to you (from the service you attend) will be notified, and you may be contacted in this regard. All the information you provide will be treated as confidential and care will be taken to ensure you cannot be identified in any reporting. While any data you provide would be included in the overall results of the research, the data will be reported in such a way that no individual participant could possibly be identified.

### *What will happen to the results of the research project?*

The results will be written up as part of a Doctoral Thesis in August 2011, and will hopefully be published in an academic journal. If you indicate on the consent form that you would like to be sent a summary of the findings when they are available, I would be happy to do this.

### *Who should I contact if I have any questions, or if I require some assistance with completing questionnaires?*

Please feel free to contact Clive Ferenbach, Specialist Psychological Practitioner, on tel. 01592 226808 if you have any questions or issues you would like to discuss, or if you require assistance with completing the questionnaires. Alternatively feel free to email me on [cliveferenbach@nhs.net](mailto:cliveferenbach@nhs.net). If you would like to make any complaint about this research, or have any general questions about taking part in research, you could contact Dr Matthias Schwannauer on tel. 0131 651 3972, or email [m.schwannauer@ed.ac.uk](mailto:m.schwannauer@ed.ac.uk).

Please take your time in considering whether you wish to participate in this research and thank you for your time in reading this.

Yours sincerely,

Clive Ferenbach  
Specialist Psychological Practitioner  
& Chief Investigator

Dr (Insert name of Lead Clinician from Unit)

Dr David Gillanders  
Clinical Psychologist

Dr Alan Harper  
Clinical Psychologist

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## Research Participant Consent Form

**Study title:** The Process of Psychological Adjustment to Multiple Sclerosis: An Investigation of the Roles of Appraisals, Acceptance, and Cognitive Fusion

**Chief Investigator:** Clive Ferenbach, Specialist Psychological Practitioner

(Please circle)

- |  |     |    |
|--|-----|----|
| - I confirm I have read and understood the attached information sheet entitled 'Invitation to Participant in a Research Project Investigating the Process of Adjustment to Multiple Sclerosis'   | Yes | No |
| - I understand that my participation is voluntary and that I can withdraw from this study at any time, without having to give a reason, without my care or legal rights being affected.  | Yes | No |
| - I understand that any data regarding my participation within this study will be stored safely, securely, confidentially and will only be accessible to Clive Ferenbach (Chief Investigator) and his supervisors (Dr David Gillanders & Dr Alan Harper, Clinical Psychologists) | Yes | No |
| - I understand that if my responses indicate that I may be suffering from significant symptoms of anxiety or depression, a relevant clinician involved in my care may be informed, so I can be contacted in regard to this.  | Yes | No |
| - I consent to my GP being notified of my participation.   | Yes | No |
| - I consent to take part in this study.  | Yes | No |
| - I would like to receive a copy of the key findings from this study. If so, please give your postal address here: _____   | Yes | No |

|                              |                         |       |
|------------------------------|-------------------------|-------|
| Signed                       | Print Name              | Date  |
| _____<br>(patient signature) | _____<br>(patient name) | _____ |
| Signed                       | Print Name              | Date  |
| _____<br>(witness signature) | _____<br>(witness name) | _____ |



Clinical Psychology Department  
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Tel: 01592 226808



**Private and Confidential**

(Insert name & address of General Practitioner)

Date: 27 July 2011  
Your Ref:  
Our Ref: CF  
Enquiries to: Clive Ferenbach  
Email: cliveferenbach@nhs.net

**Notification of a Client's Participation in a Research Project:**

**"The Process of Psychological Adjustment to Multiple Sclerosis: An investigation of the Roles of Appraisals, Acceptance, and Cognitive Fusion."**

Dear *Insert name General Practitioner*,

**Re:** *Insert details of client*

I am writing to inform you that the above client chose to participate in my research project investigating the process of psychological adjustment to Multiple Sclerosis (MS). I am carrying out this project in part fulfilment of a Doctorate in Clinical Psychology with the University of Edinburgh. This research is being conducted in collaboration between the following sites:

Fife Rehabilitation Service, NHS Fife  
The MS Service at the Western General Hospital, NHS Lothian  
The MS Service at the Royal Infirmary of Edinburgh, NHS Lothian  
The Scottish Brain Injury Rehabilitation Service, Astley Ainslie Hospital, NHS Lothian  
The Community Rehabilitation and Brain Injury Service, Livingston, NHS Lothian.

Your client was offered the chance to participate through the service listed above to which they are known. Participation simply involved completing a questionnaire pack which measured: symptoms of MS, cognitive styles (i.e. appraisals of their illness, and tendencies in their thinking), subjective well being, and symptoms of anxiety and depression. This study hopes to elucidate which 'cognitive styles' can facilitate a positive adjustment to life with symptoms of MS. There is no follow up in this study, so their participation is now complete.

Please feel free to contact me if you have any further questions, or if you would like to receive a summary of the findings once the research is complete.

Yours sincerely,

Clive Ferenbach  
Specialist Psychological Practitioner

Dr Alan Harper  
Clinical Psychologist

Clinical Psychology Department  
Sir George Sharp Unit  
Cameron Hospital  
Windygates  
KY8 5RR  
Tel: 01592 226808



**Private and Confidential**

(Insert name & address of General Practitioner)

Date: 27 July 2011  
Your Ref:  
Our Ref: CF  
Enquiries to: Clive Ferenbach  
Email: cliveferenbach@nhs.net

**Notification of a Client's Participation in a Research Project:**

**"The Process of Psychological Adjustment to Multiple Sclerosis: An investigation of the Roles of Appraisals, Acceptance, and Cognitive Fusion."**

Dear *Insert name General Practitioner*,

Re: *insert details of client*

I am writing to inform you that the above client chose to participate in my research project investigating the process of psychological adjustment to Multiple Sclerosis (MS). I am carrying out this project in part fulfilment of a Doctorate in Clinical Psychology with the University of Edinburgh. This research is being conducted in collaboration between the following sites:

Fife Rehabilitation Service, NHS Fife  
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The Scottish Brain Injury Rehabilitation Service, Astley Ainslie Hospital, NHS Lothian  
The Community Rehabilitation and Brain Injury Service, Livingston, NHS Lothian.

Your client was offered the chance to participate through the service listed above to which they are known. Participation simply involved completing a questionnaire pack which measured: symptoms of MS, cognitive styles (i.e. appraisals of their illness, and tendencies in their thinking), subjective well being, and symptoms of anxiety and depression. This study hopes to elucidate which 'cognitive styles' can facilitate a positive adjustment to life with symptoms of MS. There is no follow up in this study, so their participation is now complete.

As part of this study, your client completed the Hospital Anxiety and Depression Scale (HADS). The HADS consists of 2 subscales (both with a maximum score of 21), providing separate scores for symptoms of anxiety and depression. The recommended 'cut off' scores for an MS population are 8 for each subscale (Honarman & Feinstein, 2009). Scores above 8 may be indicative of clinically significant symptoms of depression or generalised anxiety disorder on the relevant subscales. The scores obtained from your client were as follows:

Anxiety subscale: ?  
Depression subscale: ?

Please feel free to contact me if you have any further questions, or if you would like to receive a summary of the findings once the research is complete.

Yours sincerely,

Clive Ferenbach  
Specialist Psychological Practitioner

Dr Alan Harper  
Clinical Psychologist

17 December 2010

07 January 2011

Mr Clive Ferenbach  
Trainee Clinical Psychologist  
NHS Fife  
*Sir George Sharp Unit*  
Cameron Hospital  
Cameronbridge, Fife  
KY8 5RR

Dear Mr Ferenbach

**Full title of study:** *The Process of Psychological Adjustment to Multiple Sclerosis: An Investigation of the Roles of Appraisals, Acceptance, and Cognitive Fusion.*

**REC reference number:** 10/S1103/58

Thank you for your letter of 23 December 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 15 December 2010. Please note these documents are for information only and have not been reviewed by the committee.

**Documents received**

The documents received were as follows:

| Document                           | Version | Date             |
|------------------------------------|---------|------------------|
| GP/Consultant Information Sheets   | 1.0     | 23 December 2010 |
| Participant Information Sheet: PIS | 1.1     | 23 December 2010 |
| Participant Consent Form: PCF      | 1.1     | 23 December 2010 |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.



Headquarters  
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Dr Charles J Winstanley  
Chief Executive Professor James J Barbour O.B.E.  
Lothian NHS Board is the common name of Lothian Health Board

## Second page of research ethics committee approval letter:

10/S1103/58

Please quote this number on all correspondence

Yours sincerely

**Ms Joyce Clearie**  
**Committee Co-ordinator**

E-mail: [joyce.clearie@nhslothian.scot.nhs.uk](mailto:joyce.clearie@nhslothian.scot.nhs.uk)

*Copy to:*

*Gemma Watson, The University of Edinburgh*  
*[R&D office for NHS care organisation at lead site]*



Mr Clive Ferenbach  
Trainee Clinical Psychologist  
Sir George Sharp Unit  
Cameron Hospital  
Cameronbridge  
Fife KY8 5RR

Medical Director, Primary Care  
Room 313  
Hayfield House  
Hayfield Road  
KIRKCALDY  
Fife KY2 5AH  
Tel 01592 643355  
[www.show.scot.nhs.uk/fpct](http://www.show.scot.nhs.uk/fpct)

Date 3 February 2011  
Our Ref 10-085 10/S1103/58  
NRS10/NE35  
Enquiries to Aileen Yell  
Tel No 01383 565110  
Email [aileen.yell@nhs.net](mailto:aileen.yell@nhs.net)

Dear Mr Ferenbach

**Project Title: The process of psychological adjustment to Multiple Sclerosis**

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document   | Version | Date  |
|--|---------|---|
| Research Protocol  | 1.0     | 22 November 2010  |
| IRAS R&D Form  | 3.0     | 6 December 2010   |
| IRAS SSI Form  | 3.0     | 7 December 2010   |
| Revised provisional REC favourable opinion letter (originally dated 17.12.10)                                    |         | 17 December 2010 (revised version reissued on 18 January 2011, but not redated) |
| REC favourable opinion letter confirming compliance with approval conditions set out in their letter of 17.12.10 |         | 7 January 2011  |
| NRS-CC Certificate of Compliance   |         | 28 January 2011   |

*The terms of the approval state that you are the investigator authorised to undertake this study within NHS Fife.*

The sponsors for this study are The University of Edinburgh and NHS Lothian.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr A Wood, R&D Manager, R&D Resource Centre, Lynebank Hospital, Halbeath Rd, Dunfermline, KY11 4UW ([Amanda.wood3@nhs.net](mailto:Amanda.wood3@nhs.net)) in 12 months time and subsequently at yearly intervals until the work is completed. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

All research activity must comply with the standards detailed in the Research Governance Framework for Health & Community Care (<http://www.cso.scot.nhs.uk/publications/resgov/resgov.htm>), health & safety regulations, data protection principles, other appropriate statutory legislation and in accordance with Good Clinical Practice (GCP).

Any amendments which may subsequently be made to the study should also be notified to Aileen Yell, Research Governance Officer ([aileenyell@nhs.net](mailto:aileenyell@nhs.net)), as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data.

Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or local Principal Investigator at a research site may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office ([aileenyell@nhs.net](mailto:aileenyell@nhs.net)) should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely



**DR STELLA CLARK**  
Medical Director, Primary Care  
NHS Fife

Cc : Aileen Yell, Research Governance Officer, NHS Fife, Lynebank Hospital, Dunfermline  
Pamela Shand., NHS Research Scotland C, R&D Office, Foresterhill House Annex, Foresterhil, Aberdeen AB25 2ZB

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University Hospitals Division

Queen's Medical Research Institute  
47 Little France Crescent, Edinburgh, EH16  
4TJ

CPP/MJapproval

3 March 2011

Dr David Gillanders  
Clinical Psychology Department  
School of Health in Social Science  
Old Medical School  
Edinburgh  
EH8 9AG

Dear Dr Gillanders,



Lothian

Research & Development  
Room E1.12  
Tel: 0131 242 3330  
Fax: 0131 242 3343

Email:

R&DOOffice@luht.scot.nhs.uk

Director:

Professor David E Newby

Lothian R&D Project No: 2011/P/PSY/04

**Title of Research:** The Process of Psychological Adjustment to Multiple Sclerosis: An Investigation of the Roles of Appraisals, Acceptance, and Cognitive Fusion.

**REC No:** 10/S1103/58

**CTA No:** N/A

**Eudract:** N/A

**PIS:** version 1.1 dated 23 December 2010 **Consent:** version 1.1 dated 23 December 2010

**Protocol No:** version 1 dated 22 November 2010

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

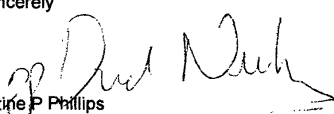
Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

  
Dr Christine P Phillips  
Deputy R&D Director

cc Mr C Ferenbach, cliveferenbach@nhs.net  
Stewart Morgan, NRS  
Dawn Lyster, QA Officer

**Z-score values for skew and kurtosis of all measures**

|                                   | <b>Z-score for data <u>pre</u>-<br/>transformation</b> |                 | <b>Z-score for data <u>post</u>-<br/>transformation</b> |                 |
|-----------------------------------|--|-----------------|---|-----------------|
|                                   | <b>Skew</b>  | <b>Kurtosis</b> | <b>Skew</b>   | <b>Kurtosis</b> |
| <b>MSIS-physical</b>              | -1.04  | -0.88           | –   | –               |
| <b>ICQ-helplessness</b>           | 0.67   | -1.92           | –   | –               |
| <b>ICQ-perceived<br/>benefits</b> | 1.22   | -1.10           | –   | –               |
| <b>IPQ-personal<br/>control</b>   | 1.80   | -1.66           | –   | –               |
| <b>IPQ-concern</b>                | -1.44  | -1.89           | –   | –               |
| <b>IPQ-<br/>understanding</b>     | <b>-3.82</b>   | 0.14            | -1.14   | -1.93           |
| <b>MSAQ-<br/>willingness</b>      | -0.40  | -0.30           | –   | –               |
| <b>MSAQ-<br/>engagement</b>       | <b>-2.18</b>   | 0.24            | 1.65  | 0.39            |
| <b>MSAQ- total</b>                | 1.46   | 0.20            | –   | –               |
| <b>CFQ</b>                        | 1.40   | 0.52            | –   | –               |
| <b>AAQ</b>                        | <b>4.17</b>  | 0.03            | <b>2.14</b>   | -1.77           |
| <b>HADS total</b>                 | <b>2.90</b>  | 0.31            | -0.86   | 0.43            |
| <b>SWLS</b>                       | 0.42   | 1.73            | –   | –               |
| <b>Age</b>                        | -0.99  | -1.08           | –   | –               |
| <b>Years since<br/>diagnosis</b>  | <b>5.89</b>  | <b>4.00</b>     | 1.80  | 0.75            |

### Results of simple mediation analyses

**Results of simple mediation analyses with MSIS-physical as independent variable, and HADS as dependent variable (no covariates included):**

|                        | Point estimate of indirect effect from bootstrapping | Standard error (SE) | BCa 95% confidence intervals |              |
|------------------------|--|---------------------|------------------------------|--------------|
|                        |  |                     | Lower                        | Upper        |
| ICQ-helplessness       | .1364  | -.0370              | <b>.0593</b>                 | <b>.2077</b> |
| ICQ-perceived benefits | -.0043   | .0083               | -.0349                       | .0044        |
| CFQ                    | .0956  | .0373               | <b>.0275</b>                 | <b>.1727</b> |
| MSAQ                   | .1163  | .0282               | <b>.0662</b>                 | <b>.1781</b> |
| IPQ-personal control   | .0317  | .0169               | <b>.0066</b>                 | <b>.0750</b> |
| IPQ- concern           | .0422  | .0164               | <b>.0171</b>                 | <b>.0836</b> |
| IPQ-understanding      | 0.0066   | .0104               | -.0393                       | .0060        |

**Results of simple mediation analyses with MSIS-physical as independent variable, and SWLS as dependent variable (age, type of disease, and years since diagnosis included as covariates):**

|                        | Point estimate of indirect effect from bootstrapping | Standard error (SE) | BCa 95% confidence intervals |               |
|------------------------|--|---------------------|------------------------------|---------------|
|                        |  |                     | Lower                        | Upper         |
| ICQ-helplessness       | -.1300   | .0337               | <b>-.1973</b>                | <b>-.0635</b> |
| ICQ-perceived benefits | .0092  | .0126               | -.0101                       | .0425         |
| CFQ                    | -.0521   | .0211               | <b>-.1002</b>                | <b>-.0165</b> |
| MSAQ                   | -.1005   | -.1013              | <b>-.1529</b>                | <b>-.0590</b> |
| IPQ-personal control   | -.0226   | .0138               | <b>-.0589</b>                | <b>-.0029</b> |
| IPQ- concern           | -.0199   | .0132               | -.0525                       | .0013         |
| IPQ-understanding      | .0051  | .0088               | -.0080                       | .0296         |